



Friends of the Foundation

CYSTIC FIBROSIS FOUNDATION FALL 2007

Fall Events Keep the "Fun" in Fundraising

Nebraska's Finest Honors CF Community Members;
Grand Island and Columbus Great Strides and Wrap Events take on New Approaches

*Nebraska's Finest Honorees
Stand Out Amongst a Crowd*

Great Strides Season Ends with Two Great Walks

Sunny skies and beautiful weather welcomed walkers to Eagle Scout Park for Great Strides Grand Island 2007 on Sunday, September 16th. Nearly 100 people joined in the fun and took great strides towards a cure for cystic fibrosis.

This year, there was a new addition to the festivities as the Grand Island walk committee hosted a Cool Car Show in conjunction with the walk. There were over 20 cars entered in the contest and attendees voted for their favorites! The walk wouldn't have been complete without wonderful snacks donated by Bosselman's. A big thank you to the Grand Island 2007 chairpersons, Todd and Kelly Usrey.

Planning for the 2008 Grand Island walk has already begun! Mark your calendars -- the walk is scheduled for **September 21st, 2008** at Eagle Scout Park in Grand Island. If you or someone you know would like to get involved on the committee or as a walker, please contact the CF Foundation office.

The Great Strides Walk Columbus was held October 13th in Columbus NE, about 30 family and friends braved the cool wet weather to show their support and readiness to find a cure for cystic fibrosis. This was the only year that weather has affected the October walk; usually the great fall weather brings more people to the walk.

The second annual Bluesfest for CF was held on October 19th at the Starlite Ballroom in Wahoo NE. "Out of the Blue" blues band from David City played red hot blues for the crowd. A chicken fried steak meal was served by the Starlite staff before the dance. A silent auction and raffle was also held.

Watch for details this next October for the third annual Bluesfest for CF, anyone wishing to be involved, or to help sponsor this worthwhile project may contact Rod or Jean Supencheck at (402) 564-6154 or rjsupen@frontiernet.net. With all of our help we hope to make CF stand for "cure found".

Columbus Article contributed by Rod Supencheck

New sights were set at this annual event which pays homage to those who have been instrumental in the fight against cystic fibrosis. 375 people attended the event at Champion's Run Golf Course on Friday, October 12th helping raise \$53,000 (a personal best for this event). This only takes a backseat to the joy of seeing such wonderful people in the CF community be honored for the perseverance they have for finding a cure for cystic fibrosis.

Many changes were made this year to the event, creating excitement and surprises throughout the entire evening. Attendees enjoyed a diverse selection of foods provided by Granite City, Wave Bistro, PF Changs, Rivera's Mexican Food, T-Bones Grillhouse, California Pizza Kitchen, Kona Grill and Champion's Run. This, along with the beer provided by Lazlo's and Quality Brands, was enough to satisfy even the hungriest attendee. Nebraska's Finest also welcomed Nebraska Governor Dave Heineman and First Lady Sally Ganem who graciously auctioned off a dinner in their home for a winning bidder at \$3,000. This was only topped by their surprise Bid for a Cure auction item, a dinner for the honorees at the governors mansion which raised a total of \$3,500.

The highlight of the evening was the presentation of awards to Nebraska's Finest. Listed below are the honorees; we are sure that after reading their biographies you will come to understand why they each are so special to the CF community.

Bridget and Erin Huddleston:

These two girls are truly inspirational. Upon meeting these two incredible girls, it is immediately clear why they are best described as independent and determined. Bridget, now 12, was diagnosed with cystic fibrosis at age four following a lengthy struggle with malnutrition and illness. Although she fought to fight to stay healthy, Bridget lives each day with a positive attitude. Bridget's younger sister, Erin, 2 ½, was diagnosed with CF at birth. While the disease has certainly affected her life, Erin's strong-will and vibrant personality allows her to live every day to its' fullest. Both girls have participated in CF clinical trials over the course of the last year and have had extremely positive results. As is common with most cystic fibrosis patients Bridget and Erin each do chest percussions and aerosol treatments as well as take medications daily to maintain their good health. Each of these girls are a delight and a bright light for the future of CF.

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Cystic Fibrosis Research

CF Research Leads to 2007 Nobel Prize in Medicine

We're including this excerpt from the CFF home page about the recent Nobel Prize winners in medicine and their connection to cystic fibrosis research in case you missed it the first time.

The 2007 Nobel prize in medicine has been awarded to three scientists for their work in creating mouse models of disease. All three of the scientists- Dr. Oliver Smithies of University of North Carolina, Sir Martin Evans of Cardiff University, and Dr. Mario Capecchi- have performed CF research that contributed to their award. The initial steps in this work began when Sir Evans isolated embryonic stem cells, making it possible to manipulate their genes to produce a "designer mouse." In work supported in part by the CF Foundation, Dr. Smithies at University of North Carolina used the stem cells to create one of the first animal disease models by disrupting the mouse CF gene.

The resulting "CF mouse" has been widely used throughout the cystic fibrosis research community, resulting in a significant impact in understanding how CF affects the various organs. Because the mouse model is so useful, development of other CF mouse strains has followed. Teaming up with researchers at the University of Iowa, Dr. Capecchi engineered a mouse to carry the mutation that is the most common in people with cystic fibrosis.

The altered mice are used by Sir Evans and many other CF researchers to study the effects of potential treatments that are geared to repair specific mutations. These studies have led directly to active clinical trials today. Sir Evans has also utilized the cystic fibrosis mouse for extensive studies in gene therapy, becoming the first to repair that CF deficit in a whole animal. The genetic manipulation techniques developed by these scientists for creation of the CF mouse model have since been used for many other disease systems, revolutionizing the study of disease processes and drug development.

Taken from the Cystic Fibrosis Foundation Website, October 8, 2007

2 New Drugs Create Promise in Pipeline

I want to share some very exciting news about two important advances in CF research. This information was communicated to the field from the national office and truly holds great promise. Please read and share with people who've contributed in the past as well as future targets.

Vertex Potentiator Trial Underway; Corrector Slated to Begin Trials by Year's End

The Vertex compound known as VX-770 has entered Phase 2 clinical testing and is in the process of enrolling 36 adult volunteers at more than a dozen care centers across the country. (To view a list of the care centers that are enrolling for this trial, visit <http://www.cff.org/research/ClinicalResearch/Find/> using keyword search VX-770.)

"This is incredibly exciting for us because it is the first oral drug to directly treat the abnormal CFTR ion transport defect in CF," said Foundation President and CEO Robert J. Beall, Ph.D. "We talk about 'shots on goal' in this disease and this is one of the most important."

The VX-770 trial studies the safety, tolerability and absorption rate of VX-770. The compound, which belongs to a category of compounds called CFTR potentiators, is believed to partially restore CFTR protein function and increase the probability that the CFTR channel is open. VX-770 may allow for increased chloride transport across the cell surface, alleviating a fundamental problem in cystic fibrosis. The previous Phase 1 trial, completed in 2006, showed that the potential drug could achieve the expected levels in the blood.

In addition, Vertex recently selected a second compound for development. The compound, known as VX-809, is expected to begin clinical development by the end of 2007. VX-809 is part of a class of compounds known as "correctors," which help the defective CF protein move to its proper place in the cell.

"These are tremendous milestones for us," said Beall. "These are the result of an historic collaboration with Vertex, which harnesses high-throughput screening for drug discovery. **These two compounds are the first by-products of our investment in high-throughput screening. If these two compounds work, they may help treat up to 90% of CF patients.**"

Both VX-770 and VX-809 were developed by Vertex Pharmaceuticals as a result of early-stage development support from the CF Foundation.

Submitted by Shannon Gubbels, Executive Director

Cystic Fibrosis in the News

CF and the Foundation Gains Public Attention Outside the CF Community

Bob Beall's Letter to Editor Featured in Washington Post

The debate over access to health care has been heating up in Washington, DC, and is critically important for people with CF. Below is a letter to the editor that appeared in the November 5th issue of the Washington Post. Dr. Beall's letter reflects the Foundation's efforts to ensure that people with cystic fibrosis have a voice in this health care debate.

The letter reflects our efforts to ensure that people with CF receive the innovative therapies that the Foundation works to develop. As the Foundation continues to speak for those with CF, you can get involved this month by asking your Member of Congress to join the CF Caucus in the U.S. House of Representatives. Visit <http://www.cff.org/GetInvolved/Advocate/> for more information.

Chronically Ill and Underinsured

Monday, November 5, 2007; Page A18

As our political leaders grapple with the important issue of providing health coverage for all children ["Vote Nearing in Battle Over Kids' Health Care," news story, Oct. 14], there is an equally challenging and often overlooked piece of the puzzle: the burden faced by people -- often with rare or chronic diseases -- who are underinsured.

At the Cystic Fibrosis Foundation, we are developing therapies that could one day lead to a cure for cystic fibrosis, a fatal genetic disease. While we're fortunate that 95 percent of cystic fibrosis patients are insured, many face a daunting reality: Despite their coverage, they may not be able to afford the advanced therapies needed to keep them alive and healthy. About 21 percent of people with cystic fibrosis say that they have intentionally skipped doses of medicine to keep costs down, and 13 percent say that they have delayed seeking treatment for the same reason.

More troubling still are those who have reached a lifetime maximum allowance on their health plans by their early 20s.

The challenge faced by underinsured cystic fibrosis patients mirrors the challenges faced by the underinsured population as a whole. This is a key part of the debate and too important to ignore.

ROBERT J. BEALL

President and Chief Executive, Cystic Fibrosis Foundation

BOOMER AND GUNNAR ESIASON, BEF FEATURED ON SPORTSCENTER

Many of you have supported the Golf Tournament and Rimington Trophy which the Nebraska CFF Chapter host in collaboration with the Boomer Esiason Foundation. Below is a link to a short, profile video featuring Gunnar and Boomer Esiason that was shown on ESPN's Sportscenter on Wednesday, November 7th, showing the motivation behind Boomer's dedication to Cystic Fibrosis fundraising.

<http://sports.espn.go.com/broadband/video/videopage?&brand=null&videoid=3097433&n8pe6c=1>

A Chance to Thank You for All You Do!

Close to 70 volunteers joined the staff of the Cystic Fibrosis Foundation at Carrabba's on 144th and Maple on November 7th for the annual Volunteer Recognition Luncheon to celebrate the pursuit of determination, endurance and the spirit of optimism. We, as a staff, were amazed with the turnout and happy to have the chance to thank those that have helped the Foundation be so successful on a local level in our fight against cystic fibrosis.

Although all of the volunteers present at the luncheon and also those who were there in spirit are special, we also were able to honor a few special individuals who have truly used their presence to make an impact on the CF community and with the Foundation. We would like to take a moment and recognize those individuals again.

Outstanding Corporate Partner– Baker's Foods

Baker's has been an exceptional partner to the cause of Cystic Fibrosis for nearly 10 years. They are heavily involved and dedicated as our point-of-purchase partner in all Omaha and metro area stores and have helped the Nebraska Chapter raise over tens of thousands of dollars for the Great Strides program along with continuously supporting the BEF Nebraska Golf Classic. Without relationships with outstanding and responsible corporate partners, such as Bakers, we would not have the success that we do.

Volunteer of the Year– Beth Craig

Beth epitomizes the qualities of an exceptional volunteer with her willingness to take initiative and her seeming inability to say no. She has given an unbelievable commitment to the foundation in both time and resources over the past ten years, running the Pat Martin Memorial golf tournament and also volunteering her time to assist with the Foundation's other four major events.

Volunteer MVP– Mark Lisko

Mark has an outstanding commitment to cystic fibrosis and the foundation and uses his cheerful disposition and compassion to help with the Travis Ferguson Memorial Fishing Tournament. Mark and the Aksarben Bass Club handle many of the details for the preparation and day of the tournament, donating both time and resources to help the event succeed.

Breath of Life– Dee Acquazzino

It is only appropriate that Dee be recognized for her 30 year commitment to cystic fibrosis. She began working at the UNMC CF Care Center in 1977 and has collaborated with the CFF to further our fundraising efforts in every feasible way. Dee has been and continues to be a true advocate for cystic fibrosis patients with her passion for her career and assistance to the Foundation.

Board Member of the Year– Ed Shada

Ed has made a significant contribution to the Nebraska's Finest committee and leverages his relationships to benefit the success of the event. Ed continues to give by recruiting board and committee members and is constantly cultivating relationships to grow awareness of cystic fibrosis throughout Nebraska. He is dedicated to pursuing new opportunities and is always looking for the betterment of the Foundation, with his sights set on a cure.

Board Rising Star– Jeff Jorth

Jeff's energy and stick-to-it-iveness are what make him the 2007 Board Rising Star. After his first board meeting Jeff agreed to co-chair Great Strides Omaha, an event that eventually has raise nearly \$250,000 (surpassing it's goal by quite a bit). Jeff was the driving force behind the Great Strides committee meeting their sponsorship goal of \$60,000 in 2007 and continues to push forward to capitalize on the Omaha market. He is an incredible asset to the board and to the Foundation.

Board MVP– Laurie Baedke

Laurie continuously steps in to assist in any way possible. Laurie has served on the Rimington Trophy committee, works as a New Board Member Development chair, forms Great Strides teams, along with many other things. She is forever envisioning ways to improve the board and the relationships between board members and the Foundation and is one of the key reasons we are able to experience success as an organization.

Lifetime Achievement Award– Tom and Peg Barrett

Tom and Peg have been active with the CFF following their grandson, Mitchell's, diagnosis. The pair has been instrumental in developing the Lincoln Great Strides walk and running every aspect of the event for many years. They are focused on growing support for CF in their community becoming involved even further by assisting with health fairs, volunteer projects and cheer leading the Foundation staff. They also have been very active with Concerned Nebraskans for Cystic Fibrosis and assist in fundraising efforts for patient's needs in addition to helping the foundation. It is an absolute joy to work with such a committed couple!

Inspirational Award– Thad and Tamara Franklin

Thad and Tamara are a true testament of what it means to love your child with everything that you have. Both are committed to bettering the life of their daughter Victoria and funding research to extend life for all people living with CF. A board member for over three years, Thad has shown his compassion for those living with the disease and has leveraged his relationships to further the success of the Foundation. From his committee participation on the Nebraska Golf Classic to his involvement on Great Strides, we are honored to have Thad and Tamara's support and join them in the desire to make CF stand for Cure Found.

Wet Golfers Help See Sunnier Days in CF Research

The 10th Annual Patricia Martin Golf tournament was held at Quarry Oaks on October 14th.

Despite the rainy weather, 80 golfers attended and enjoyed 18 holes of golf, lunch, awards ceremony and a raffle drawing. The golfers need to be commended on enduring the weather and maintaining a positive attitude throughout the day. One golfer summed it up pretty well "Any day golfing in the rain is always better than a day on the couch".

Joe Sutter and team did a fabulous job of setting up the club house for our use, placing the flags on designated prize holes and awarding the top three teams. We also would like to thank Qdoba, Omaha Meat Processors and Tiger Toms for helping sponsor this event.

Once again we had a outstanding team of volunteers that obtained donated food and prizes, registered golfers, sold raffle tickets, etc. The volunteers are what make this tournament run seamlessly.

A big thanks to the golfers and the wonderful volunteers for a successful 2007 tournament.

The organization for the 11th golf tournament is well underway and will be held at Quarry Oaks sometime late 2008. We are looking forward to meeting the faithful supporters and seeing new faces.



Still smiling, even in the rain!

Contributed by Beth Craig, Pat Martin Golf Tournament Chair

Nebraska's Finest-- Continued from Page 1

Philip Stalnaker:

Since his initial diagnosis of cystic fibrosis at seven months, Philip has had to find ways to keep his illness in check. He is determined to live a full life and does whatever it takes to keep himself healthy. Staying diligent and aggressive with his therapies and medicines gives him the freedom to live without the limitations CF imposes.

Much of the credit for his success is undoubtedly attributed to the CF Care Center at UNMC, where he has been a patient since diagnosis. After transitioning to the adult care center and Dr. Peter Murphy's care a few years ago, Philip has seen record PFT scores and continues to thrive. He has also been active in drug trials that are aimed at developing better treatments and ultimately a cure for this disease. Philip fully believes that with the help of his doctors, his family, and God, there is every reason to believe that he will enjoy his life for decades to come.

Nancy Hanson

Nancy Hanson makes an impact on the cf community every day. An employee at Creighton University, Nancy conducts research that is making a difference in the lives of those who live with and suffer from the effects of cystic fibrosis. Nancy received her training in virus research and as such, became interested in bacteria and their resistance to antibiotics. As a faculty member of the antibiotic research group at Creighton University she had the option to explore this relationship further. Through her research, Nancy became aware of the problems cystic fibrosis patients face with respect to lung infections, in particular, *Pseudomonas aeruginosa*. In a vital collaboration with Dr. Paul Sammut, Dee Acquazzino and the CF Care Center research has moved forward. This was possible by a generous grant from the John A. Wiebe, Jr. Children's Healthcare Fund through Children's Hospital Foundation in Omaha. These studies and the research that Nancy has focused her career on is hugely beneficial for those who live with cystic fibrosis.

Jim Killips

Jim Killips is a pioneer in helping CF families. Born in California, Jim and his mother moved to Omaha when he was a young boy. In his late 20's, Jim received a life-changing diagnosis. He became extremely ill with cancer and spent the next year and a half in and out of the hospital. Jim was not expected to survive his battle, but following intensive treatment he experienced a full recovery. It was at this point Jim's life changed and he began giving back to terminally ill patients. He started his journey with children at the University of Nebraska Medical Center and spent time with nearly 100 kids, 27 of which lost their fight.

Through the years, Jim became acquainted with many of the children's parents. In addition to counseling children, Jim assisted families by providing them with a place to stay throughout their child's treatment. It was the partnership between Jim and a child's parent that established the Omaha Chapter of Make-A-Wish. Ironically enough, the first child who was granted a wish, was a CF patient. Jim was deeply impacted when this young person lost their battle and has been involved with the CF Foundation ever since.

Some of Jim's other accomplishments include traveling the University circuit giving lectures on death and dying. He has also been heavily involved in a North Omaha organization known as the Good News Bears. Over the course of the last 16 years, this group has helped less fortunate children find a better path in life. The generosity that Jim embodies is not limited to activities outside his home. Jim and wife Liz have graciously opened their hearts to 30 foster children. A passion initially driven by Liz, but now shared equally. Jim also sits on the CFF Board.

The fun didn't stop after the presentation of awards. The crowd enjoyed the very engaging motivational speaker Gus Gustafson. Afterwards the CF Care Center employees took control of the dance floor and showed the rest of us how to end a party, dancing to the music of High Heel.

The staff wishes to send out a huge thank you to the committee who were responsible for a large part of this event's success. This phenomenal committee included chair Bobbi Christensen who was joined by John Aesoph, Seth Tracy, Ed Shada, Beth Haley, Toni Brasher, Scott Johnson. We would also like to give a special thanks to CFF Board Member Leon Thomas and his volunteers and company Jelecos Systems, Inc. for providing the systems, setup and personnel for checking in and checking out the event's guests.

The committee has already started brainstorming on Nebraska's Finest 2008. Please contact the office if you have any comments or suggestions, or wish to be a part of the planning committee.

Contributed by Bobbi Christensen, event chair, and Ashli Brehm

From the Care Center

We are nearing the completion of the second year of our CF Newborn Screening Program for the state of Nebraska. The program has been very successful and has resulted in diagnosing many newborns since its inception in January, 2006. Achieving this success is important to the health of each of these children as this allows us to identify these infants before they become ill and initiate treatment to maintain their health. We are fortunate to be able to work with a team of newborn screening specialists in the Nebraska Department of Health and Human Services who are doing an excellent job of providing quality services to the children of this state and hope that with the continued success of this program, we will have a healthier group of people with CF.

Submitted by Dee Acquazzino, UNMC Clinical/Research Coordinator



Don't Forget to Sign Up for Great Strides!

Sign up today by visiting
[Http://www.cff.org/great_strides/](http://www.cff.org/great_strides/)

Take a greater step for a cure towards cystic
fibrosis and renew your commitment to
Great Strides 2008.

Don't Let Anyone Give You a Bad Gift Ever Again!

Create A Gift Registry For Cystic Fibrosis

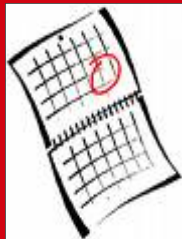
Forget about getting a pound cake or ugly sweater this year for the holidays!
Follow the steps below to create your own personal CFF Gift Registry

1. Go to the Cystic Fibrosis webpage at www.cff.org
1. Select the link for "Make a Donation" on the bottom right hand side
3. Select "Create a Gift Registry" and follow all steps
4. Notify your guests, family and friends that you would prefer a donation be made in your honor to the Cystic Fibrosis Foundation and that you have registered online.

Gifts can also be sent to the office at:
Cystic Fibrosis Foundation—
Nebraska Chapter
11917 Pierce Plaza
Omaha, NE 68144

Gift Registries can be found by
selecting "Create a Gift Registry" and
going to the "Find a Registry" Link.

*Tell Your Friends to Forget the Wrapping Paper and Card & Instead
Help You Give the Gift that Keeps on Giving Memories to those with cystic fibrosis!*



Mark Your Calendars!

Important upcoming events and dates for this month.
For More information on any of these events please
contact the CFF office at (402)330-6164



Shop Till You Drop!

**Material Girl Purchases
Benefit CFF!
(Just in time for the Holidays!)**

**Material Girl,
a premier handbag
and accessories boutique,
located at
11748 Stonegate Circle
is devoting the entire month
of November to help raise funds for
Cystic Fibrosis.**

**Mention that you came on behalf of the
Cystic Fibrosis Foundation and 10% of any
purchase will be donated
back to the Foundation.**

**For more details
Call the CFF office or
Material Girl at 402-505-4437**

Cystic Fibrosis Scholarship Foundation Applications Due

Information for Possible Recipients

The program is available to those with CF who will be enrolled in an undergraduate program or vocational school in the fall of 2008. **Scholarships will be awarded based on a combination of financial need, academic achievement, and leadership.** Awards may be used for tuition, books, and room and board. Awards will be sent directly to the institution that the student will be attending. Both single year and multi-year awards are available, generally for \$1,000 per year. Students can reapply the following year for an additional award, but there will be no guarantee of receiving a scholarship.

Applications will be accepted starting on January 15, 2008 and must be received and postmarked by March 21, 2008. They may be sent to:

Cystic Fibrosis Scholarship Foundation
1555 Sherman Avenue, #116
Evanston, IL 60201

Applicants will be notified by April 20th, 2008.

Applications and more information can be found at the Cystic Fibrosis Scholarship Foundation website at: www.cfscholarship.org

Rimington Trophy

Saturday, January 12th, 2008

**Join the Boomer Esiason Foundation and Cystic Fibrosis Foundation's
Award Banquet for NCAA Football's Premier Center
At the Rococo Theatre in Lincoln.**

**Black Tie Optional
Featuring a live and silent auction,
Dinner and Trophy Presentation**

**All proceeds benefit the Nebraska Chapter of the CFF
Contact the office at 330-6164 for sponsorship and table information.**