

# CONNECTION

NEWS PUBLICATION OF THE CYSTIC FIBROSIS FOUNDATION

**Calendar of Events:**

- November 27:  
Northwest Arkansas Wine Opener Committee Meeting  
Rogers, AR
- November 30:  
Little Rock Wine Opener Committee Meeting  
Little Rock, AR

## CFF NAMED CHARITABLE ORGANIZATION OF THE YEAR

The Cystic Fibrosis Foundation was selected as the 2006 Charitable Organization of the Year by USA Track & Field (USATF), the national governing body of track and field, long-distance running and race walking.

The CF Foundation was honored for its largest fund-raising program-GREAT STRIDES-a national walk that raised nearly \$32 million in 2006, and for other road races, jogs and marathons that raise money to support vital CF research and care programs. Craig A. Masback,

CEO of USATF, noted that the CF Foundation has developed one of the nation's most successful fund-raising program by appealing to Americans' desire to take action-not simply donate funds-for a cause.

As part of GREAT STRIDES, more than 200,000 coworkers, friends, and family come together each year to walk in support of one cause: a cure for CF. GREAT STRIDES features nearly 600 walk sites, with participants walking as individuals or teams to raise money for CF. Since the first GREAT STRIDES walk in 1989,

approximately \$250 million has been raised.

Since 2002, USA Track & Field has studied the impact of charitable walking and running in the United States. The annual award, based on USATF's studies, recognizes charitable organizations like the CF Foundation that have successfully advanced their cause through walks and runs. Previous winners include the Susan B. Breast Cancer Foundation Race for the Cure and the American Heart Association Heart Walk.

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## VERTEX POTENTIATOR TRIAL UNDERWAY

The Vertex compound known as VX-770 has entered Phase 2 clinical testing. "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. The compound is believed to partially restore CFTR protein function and increase the probability that

the CFTR channel is open. In addition, Vertex recently selected a second compound for development. The compound, known as VX-809, is expected to be in clinical development by the end of 2007. VX-809 is a 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 mile-

stones for us," said Beall. "If these two compounds work, they may help treat up to 90% of CF patients." Both VX-770 and VX-809 compounds were developed by Vertex Pharmaceuticals as a result of support from the CF Foundation.



## MESSAGE FROM THE DIRECTOR

*"People - generous, dedicated, and extraordinary people are at the heart of all we do"*

Robert J. Beall, Ph.D.  
President & CEO  
Cystic Fibrosis  
Foundation

There are so many things to be thankful for this year. I am thankful that we could open a beautiful office that gives us a presence in this growing area. I am grateful for the donations and commitments made of over \$125,000 in the last four months.

I am thankful that through the tireless help of volunteers we could facilitate so many fun, successful events to support a vital mission. I am so appreciative of Kesley Hays, April

Pennington, and Guy and Joy Dillahunty who volunteer to help with administrative tasks at the office.

Amazed at the progress in scientific research and gene therapy, I am thankful that the CF Foundation is so focused on the important task of improving the quality of life for people with CF and finding a cure.

I am grateful for the CFF Board of Directors who volunteer their time to provide

overall direction for the Foundation. I am also thankful that we are making plans to hire a staff person in 2008 so we can continue to move this Foundation forward.

This year at Thanksgiving, I am thankful for every volunteer that gives their time or resources, and every business or individual who supports our mission financially.

Happy Thanksgiving!

## 2008 EVENT CALENDAR



Wine Opener-Little Rock  
April 17, 2008

Catch a Cure Bass Tournament-Central Arkansas  
April 2008

Wine Opener-Northwest AR  
April 2008

GREAT STRIDES-Fort Smith  
May 10, 2008

GREAT STRIDES-Benton  
May 10, 2008

GREAT STRIDES-Jonesboro  
May 17, 2008

GREAT STRIDES-Little Rock  
May 17, 2008

Ozark's Charity Golf Classic-Rogers  
June 2008

GREAT STRIDES-Bentonville  
September 6, 2008

GREAT STRIDES-Hot Springs  
September 6, 2008

Swing for a Cure Golf Classic-Little Rock  
September 2008

Breath of Life Gala-Little Rock  
November 2008

## CONGRESSIONAL CYSTIC FIBROSIS CAUCUS

The CF Foundation has an ambitious goal to recruit 150 members of Congress to join the Congressional Cystic Fibrosis Caucus by year's end. The Caucus plays an important role on Capitol Hill by helping to increase awareness and support for the issues that matter to all people with CF. To reach its goal,

the Foundation is calling on volunteers to get involved in this advocacy effort.

There are tools and templates available in the Advocacy section of the CFF web site that will help make it easy to ask members of Congress to become a member of the Congressional CF

Caucus.

We are focusing on recruiting Congressman Vic Snyder, Congressman John Boozman, and Congressman Mike Ross. If you would like to help contact your Congressman, please contact the Arkansas Chapter office.



## VOLUNTEER SPOTLIGHT

The Cystic Fibrosis Foundation is grateful to Chip & Charlotte Stacy who continuously give their talents, resources, and time to the CF Foundation. Chip and Charlotte both practice law with the Hood & Stacy law firm in Bentonville and they have two children, Caroline and Trey. Their son Trey has cystic fibrosis.

They spent countless hours volunteering their time to help plan the Northwest Ar-

kansas GREAT STRIDES. The funds raised directly through their walk team and corporate sponsors totaled over \$35,000. This couple also participated in the Ozarks Charity Golf Classic; Chip recently signed on to Chair the golf classic in 2008.

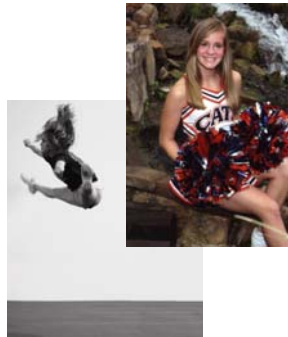
Not only have they taken fundraising to the next level, they lead by example. Chip and Charlotte Stacy are the first in the state of Arkansas to contribute a major gift in

the amount of \$10,000. "I give to the CF Foundation because I truly believe that there are drugs in the pipeline that will lessen the symptoms of CF greatly," Chip Stacy said. 100% of every major gift donation goes directly to scientific research and because of people like them we continue to make milestones to a cure. We are so thankful to Chip and Charlotte for being the extraordinary people that they are and for giving so much to the CF foundation.



## KIDS CORNER HIGHLIGHT

**Cheer for CFF:** Kailee Wood, a sophomore at Har-Ber High School in Springdale is an inspiration for those who have cystic fibrosis. She is an honor student and the co-captain of the Junior Varsity cheerleading squad. In her spare time she is active in gymnastics, competitive cheerleading, and her church. She is already planning for her future collegiate career as a pre-med student with the goal of becoming a OBGYN. We are very proud of Kailee!



## CUREFINDERS

On December 10-14 we will kick off the CureFinders program in several schools across the state. Students in Arkansas will be bringing their change to school to raise money to find a cure for CF. This is a fun activity that teaches them about the importance of charitable giving. There is still time to sign up your child's school for this fun activity.



## GIFTS FOR A CURE

Looking for the perfect gift that will never be thrown away or go out of style? Send e-Cards through the CFF web site to friends, family, and colleagues and support the mission of the CF Foundation! You can send e-Cards for birthdays, holidays, or other special occasions by visiting the website ([www.cff.org/gifts](http://www.cff.org/gifts)).

Another way to support the CF Foundation this holiday shopping season is to make your online gift purchases through "Clicks! For Cystic Fibrosis"; a website that donates a percentage of every online sale to the CF Foundation. Simply access the website, find a retailer from the directory, and make your purchases.

There is a selection of hundreds of online retailers, including Amazon.com, Wal-Mart, Macy's, EBay, Barnes & Noble, Old Navy, Cabala's, The Gap, Linens-N-Things, and many more! ([www.clicksforcf.com](http://www.clicksforcf.com))





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CYSTIC FIBROSIS FOUNDATION

Jennifer Maune  
Director  
Arkansas Chapter  
200 South Commerce, Suite 100  
Little Rock, AR 72201  
  
Phone: 501-371-0233  
Fax: 501-324-2236  
E-mail: arkansas@cff.org

**Adding tomorrows every day!**

<http://arkansas.cff.org>

The Cystic Fibrosis Foundation was founded in 1955 by a dedicated group of parents whose children had cystic fibrosis (CF). CF is a life threatening genetic disease that causes the body to produce an abnormally thick, sticky mucus which clogs the lungs and leads to fatal lung infections. To date, there is no cure for cystic fibrosis. The mission of the Cystic Fibrosis Foundation is to assure the development of a means to cure and control CF and improve the quality of life for those who have the disease. In 1955, children with CF typically did not survive to reach elementary school. Today, the median age of survival is more than 37 years.

Over the past 50 years, the CF Foundation has pursued its mission through two strategies: (1) establishing and accrediting more than 117 centers throughout the United States to care for CF patients and (2) supporting medical research to find improved therapies and a cure.

The local office of the CF Foundation is the Arkansas Chapter. The Arkansas Chapter supports the mission of the Cystic Fibrosis Foundation by hosting multiple fundraising events in Arkansas and supporting a number of community events organized by CF families and friends.

## CALENDAR OF EVENTS

Date	Event	Contact	Location
November 27 12:00 pm	NWA Wine Opener Committee Meeting	Greg Campbell (479) 631-3116	Signature Bank of AR 3710 Southern Hills Blvd. Rogers, AR
November 30 12:00 pm	Little Rock Wine Opener Committee Meeting	Taylor Adams (501) 312-7252	Merrill Lynch 2200 N. Rodney Parham Rd. Suite 300 Little Rock, AR