



BLOW AWAY CYSTIC FIBROSIS 2012



National Champions

The College Football National Championship Title will stay in the great state of Alabama for the third consecutive year. Regardless of your college affiliation, that is something to be proud of.

Something else we can be proud of is all the research being conducted to find a cure for cystic fibrosis. Alabama hosts many brilliant researchers that have played significant roles in the fight to cure CF. Every year they make amazing discoveries and work diligently to improve the lives of patients and families dealing with cystic fibrosis.

The Alabama football team chose to perform at the peak of their abilities to become national champions. This year we can become champions in the fight to cure cystic fibrosis. Each one of us can choose to improve our own personal performance, to raise our goals, to add more team members, to reach more people or to add a fundraising event to our current efforts.

What are your plans to get more fundraising touchdowns for your team? We would love to hear your plans to really become a CF champion this year.

Sincerely,

Tonia Beverly, Editor



2012

January, 2012

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Rock the Night

-Decatur Daily 1/11/12

Its time for the second annual Rockin' for a Cause Cystic Fibrosis Silent Auction. The event will be March 17 from 7-10 p.m. at The Brick Deli. Stan and Shannon Anderson organized this event to raise money for the Cystic Fibrosis Foundation in hopes of finding a cure for the millions of people diagnosed with the disease, including their daughter, Ella Kate.

Are you Registered?



This is a fun night of great music and a variety of silent auction items. Several local bands will donate their time to play that evening. If you are interested in donating an item for the silent auction or making a contribution to the Cystic Fibrosis Foundation, contact Shannon at 256-303-9210.

Host your own

Let us know what you are working on. We will add your fundraising event to our website, the newsletter and to our facebook status.

Send us your flyer, link and event information to Alabama@cff.org.

Shaye Brunner - Motorcycle/Boat Poker Run & Concert - Montgomery, AL Fall

Marshal Brooks -
Boaz 5k- Fall

More information will be available on these and more volunteer led events as they become available.

Upcoming Events

Not much of a walker? Don't worry we have other events that may be right up your alley! Encourage your company to sponsor one of these great events or invite your clients to join you and make your business meeting fun for a great cause.

- * Breath of Life Gala- August
- * Bay Area's Finest - September
- * Shoot for a Cure (Clay Shoot)
- September 7th
- * Mobile Swinging Fore A Cure Golf
- October
- * Climb for a Cure - October 21st
- * Birmingham Tee Off Fore A Cure (Golf) -
October
- * Birmingham's Finest- November 8th

Great Strides is the Foundation's largest fundraising event. It provides opportunities for all people within a local community to get involved forming teams through their workplace, through clubs and organizations or with friends and family. Walk day is a fun, family-oriented celebration that includes a healthy walk, Kids' Corner activities, food, and festivities that participants look forward to year after year.

Where to Stride	Date	Check In Time
Montgomery - Hampstead	4/21/12	9:30 AM
Tuscaloosa - Snow Hinton Park	4/21/12	9:00 AM
Auburn - Town Creek Park	4/28/12	9:00 AM
Dothan - Kiwanis/Westgate Park	4/28/12	8:30 AM
Huntsville - Bridge Street Centre	5/05/12	9:00 AM
Birmingham - Veterans Park in Hoover	5/19/12	9:00 AM
Mobile/Eastern Shore - USA Track	5/19/12	8:30 AM
Anniston - Oxford Lake Park	6/2/12	9:00 AM

Look for February Frenzy emails from your walk partner about exciting incentives for getting your team registered now!

To learn more about Great Strides or to register your team, please [click here](#).

Vertex Plans Additional Studies

January 9, 2012

Vertex Pharmaceuticals Inc. announced yesterday it plans to begin clinical trials of the potential cystic fibrosis therapy Kalydeco™ (VX-770) in more patient groups later this year, including in children as young as 2 years old.

Kalydeco (kuh-LYE-deh-koh) is under review by the U.S. Food and Drug Administration (FDA) for approval in people ages 6 and older with the G551D mutation of CF.

The FDA has granted Vertex a six-month priority review of the drug, setting a target date of April 18 for the approval decision. If approved, Kalydeco would be the first drug available that targets the underlying cause of CF.

Vertex is planning clinical trials of Kalydeco in patient groups that were not evaluated in earlier Phase 3 studies of the drug, including:

- Children ages 2 to 5 with gating mutations, including G551D.
- People with other gating mutations besides G551D.
- People with at least one copy of the R117H mutation of CF.

In gating mutations like G551D, the defective protein in CF moves to its proper place at the surface of the cell but does not function correctly. The CFTR protein instead acts like a locked gate, impeding the proper flow of salt and fluid in and out of the cell. Kalydeco aims to unlock that gate and help restore the function of the defective protein.

G551D is the most common gating mutation, accounting for about 4 percent of people with CF in the United States. The remaining gating mutations are found in about 1 percent of the CF population.

The R117H mutation, known as a "conductance mutation," causes abnormal function of the CFTR protein at the cell surface. About 3 percent of people with CF in the United States have this mutation.

Kalydeco is also being tested in an ongoing Phase 2 trial in combination with another potential therapy, VX-809, in people with the most common mutation of CF, Delta F508. In addition, Vertex plans to launch a clinical trial in mid-2012 studying Kalydeco with another therapy in development, VX-661, in people with the Delta F508 mutation.

The CF Foundation worked with Vertex to discover Kalydeco, VX-809 and VX-661 and provided substantial financial and clinical support throughout the development process.

Contact Us

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The Cystic Fibrosis Foundation welcomes you to its annual Great Strides walk-a-thon to raise money for CF research and care. Because of health risks to people with CF, it is the policy of the CF Foundation that individuals with CF who have had a positive sputum culture for Burkholderia cepacia complex (B. cepacia) shall not attend events or meetings sponsored by the CF Foundation.

[To learn more, review the CF Foundation's policy on infection control.](#)

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