

We Are

Making a difference in the
fight against cystic fibrosis.



Cystic Fibrosis Foundation, Central Texas Newsletter

Summer Newsletter

June 2009

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Pluckers - Party with a Purpose

This Spring, Pluckers teamed up with their friends at KGSR to create a series of Thursday night Happy Hours featuring one local charity each week. From 6 to 9pm, Pluckers will be donating 20% of all food and non-alcoholic beverage purchases back to the featured charity. They are calling this A Party with a Purpose.

6/18

Band: Beaver Nelson

Charity: Cystic Fibrosis Foundation

At Pluckers on South Lamar starting at 6pm.

Listen to KGSR from June 14th - June 18th to hear our CF ad aired over the radio!



Austin GREAT STRIDES....

The Austin GREAT STRIDES was held at a new location this year, the Austin Zoo. Held on May 9th, nearly 600 striders enjoyed the animals and festivities. That's 200 more than last year! The goal for Austin this year was \$154,000, and as the date grew closer, we were projecting \$140,000, which is \$7,000 more than last year. Currently, we're at \$118,474 with money still coming in. If everyone will continue to conduct their letter-writing campaigns, follow up on letters they've sent out, and collect money, we should reach the \$140,000. As long as the money comes in by December 31, 2009, it counts toward your team. If you want to put together a wrap around event, we will be happy to help you. The top fundraising team for Austin was Buller Buddies, coming in at a total of \$12,840.

We want to recognize a couple of other Austin teams. Erin Green, a junior at Bowie High in Austin, is the team leader and became involved, because one of her friends has a little sister, Sophie, who has cystic fibrosis. Last year, Erin's team, Saving Sophie, raised \$2,139. This year, with proceeds from a car wash, bake sale, luau, t-shirt sales and necklace sales, the team raised \$5,293.

We had a few teams combine at the event, so we'll just call the group Ingram's Eagles. Technically not a new team, this group ended up being a super team with over 78 walkers, and most of them were high school kids! Katie Ingram, twin sister to Emily, who was our CF ambassador for the event, rallied her church youth



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2009 Up Coming Events

Rick Barnes Golf Classic

Sept. 18-Pre Tournament Dinner
Sept. 21-Tournament

UT Austin Men's Basketball Coach, Rick Barnes, is the Honorary Chairperson for this annual event. Break out the sticks and have a ball with this "par is your friend," four-man scramble format at the impressive University of Texas Golf Club.

Sports Challenge

Oct. 24, 2009

Everyone from weekend warriors to serious athletes to those who just like to have fun are invited to participate in this half-day event where teams sponsored by area companies compete in mini-Olympic style events. Awards will be presented to the top three winners of each event, as well as the team with the most spirit.

Black Tie & Boots Ball

Nov. 14, 2009

We are excited to announce that this year's gala will be held at the Bob Bullock Texas State History Museum. The night will be filled with live music by Walt Wilkins, and there will be a live and silent auction.

Central Texas Chapter

CF ambassador for the event, rallied her church youth group, and Emily rallied her fellow high school band members. Together, their team raised \$6,837!

We want to thank our wonderful sponsors and donors: Solvay, American Airlines, Gilead, Austin Zoo, Perkin Elmer, Blue Cross Blue Shield, Run Tex, McDonalds, and BJ's Restaurant & Brewery.....Great job, Austin!



Temple Great Strides

The Temple GREAT STRIDES was held on April 18th. For the 2nd time in three walk seasons, we were rained out of the

original venue, but that did not stop 100 walkers from coming out and celebrating the day. The goal for Temple this year was \$22,000, and currently, we're just shy of that number. With donations still coming in, it won't be long till the \$22,000 is reached. The top fundraising team was Macy's Biggest Fans, coming in at a total of \$9,740. Temple's wonderful sponsors and donors were The Children's Hospital at Scott & White, BJ's Restaurant, Christian Life Church, American Home Patient, and Temple Fire Dept. Great job, Temple!

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Addresses Basic Defect, Enters Pivotal Clinical Trials

May 27, 2009
Vertex
Pharmaceuticals

Incorporated announced today the initiation of a Phase 3 registration program for VX-770, a promising oral drug aimed at treating the underlying cause of cystic fibrosis (CF).

This registration program is designed to generate data that the U.S. Food and Drug Administration can use to determine if VX-770 is safe, effective and acceptable for approval. The VX-770 registration program will consist of three different clinical trials, including:

A primary 48-week trial for patients age 12 years and older who carry a G551D mutation of CF;

A 48-week trial for patients ages 6 to 11 years who carry a G551D mutation of CF; and

A 16-week trial to evaluate for the first time patients age 12 years and older who are homozygous for the Delta F508 mutation of CF, the most common mutation in CF patients.

"The initiation of the VX-770 registration program is a major advancement in our efforts to bring forward a new therapy aimed at treating the underlying cause of CF," said Robert J. Beall, Ph.D., president and chief executive officer of the Cystic Fibrosis Foundation.

"This investigational drug represents one of the most promising routes to changing the course of this disease, and we are encouraged with the progress of both VX-770 and VX-809, which recently entered a Phase 2a clinical trial in CF patients."

VX-770 is being developed and tested by Vertex, with support from the CF Foundation. The potential drug aims to open the chloride channels that do not function.

For more information about these trials, call the clinical trials hotline operated by Vertex at (877) 634-8789.

[Read the Vertex Pharmaceuticals Inc. News Release.](#)

[Learn more about VX-770 and VX-809.](#)

