

## GREAT STRIDES Brings in \$406,000

Wow, what a weekend! The Carolinas Chapter-Charlotte Office of the Cystic Fibrosis Foundation raised an astonishing \$406,000 for CF research at this year's GREAT STRIDES Walk-a-thon! With more than 1,000 walkers at five different walk sites, pizza served, goodies were eaten, all had fun and lots of *money* was raised to fight cystic fibrosis.

GREAT STRIDES 2007 is just around the corner, and we need to keep the momentum going! Thanks to the amazing volunteers, our sites continue to raise more money year after year. As we approach the 19th Annual GREAT STRIDES Walk-a-thon, we want to grow our committees and welcome new individuals who would like to take part in this tremendous event. Please contact Amy Brindley for the Charlotte walk or Ashley Suddarth for all other walk locations, at (704) 321-7852 or [abrindley@cff.org](mailto:abrindley@cff.org) / [asuddarth@cff.org](mailto:asuddarth@cff.org), for more information. ■

### Top Teams as of 8/1

The 2006 Great Strides walk was a record-breaking year for our family teams.

Congrats to our 'Shining Stars' on their efforts to go above and beyond in their efforts to raise funds for CF!

#### Charlotte

1. Team Maya
2. Will's Team
3. A-Team

#### Asheville

1. Team Hopeful Ones
2. Zero Gravity
3. Parker Pals

#### Salisbury

1. Team Gage
2. Peanut Patrol
3. Team 'Rella

#### Lake Norman

1. Team Gracie
2. Team Ava (New Team)
3. Rachel's & Amy's Racers

#### Independence

1. Haga Family

## Families and Corporate Teams join forces to find a cure for CF

Great Strides, the CF Foundations' largest national fundraiser since 1988 took place throughout the Carolinas during May and June. Families, corporate teams and individuals collected donations to support vital CF research and care programs. Local chapter walks took place in Asheville, Salisbury, Lake Norman, Independence, VA and Charlotte.

Through our volunteer and family efforts, to date, we have raised just over \$406,000 toward our quest for a cure and the total continues to rise! The walk signifies hope, hope of time when CF will stand for **Cure Found!**

The CF Foundation faces a new challenge, for the first time in recent history, CF scientific opportunities are coming at a pace that is exceeding the CF Foundation's ability to fund them. The dollars raised through Great Strides are buying science, and science buys life.

Our local CF staff cannot thank our family and corporate teams and in-kind sponsors enough for their tireless efforts on behalf of our shared goal.



Special thanks to our sponsors (\$5,000+):



**Upcoming CFF Events:****General Electric Rosebuds  
Golf Tournament**

River Run Golf & Country Club  
Monday, September 25<sup>th</sup>

**20th Annual Tennis  
Challenge and Ball**

Old Providence Racquet Club  
& Quail Hollow Club  
Saturday, October 7th

**Shoot For A Cure**

Charlotte Rifle and Pistol Club  
Saturday, November 4th

**Breath of Fresh Art**

Blue Restaurant & Bar  
Wednesday, November 8<sup>th</sup>

For more information concerning the  
above events, please contact the  
CFF Charlotte Office at  
800.336.0329 and 704.321.7852 or  
by email, [charlotte-nc@cff.org](mailto:charlotte-nc@cff.org).

**GE Volunteers Rosebuds for CF Golf  
Tournament – September 25, 2006**

The Cystic Fibrosis Foundation, with the help of GE Volunteers\* announce the 3<sup>rd</sup> Annual Rosebuds for CF Golf Tournament.

This year's tournament is presented by:



This year's tournament will be held on Monday, September 25, 2006 at River Run Country Club in Davidson. For more information on how you can get involved please contact Sabrina Watt at 704.321.7852 or [swatt@cff.org](mailto:swatt@cff.org).

\* GE Volunteers, a global organization made up of GE employees and retirees, helps strengthen GE communities through effective and sustainable volunteerism. Each year, more than 1,800 individual volunteer projects are implemented around the world, with major emphasis on education, human services and the environment. In 2003, approximately 53,000 GE Volunteers spent over one million hours of service in 46 countries.

## Median Survival Age Increases to 36.8 Years

We are pleased to report that the median age of survival for a person with CF has risen to 36.8 years—up from 35.1 in 2004!

For decades, the CF Foundation has tracked the health and longevity of patients treated through its innovative care center network. Caregivers at these centers collect confidential vital statistics from CF patients who visit, which skilled statisticians then analyze and convey in the annual CF Foundation Patient Registry Report.

**In the last four years alone, we have added more than five years to the median survival age of CF patients.**

We attribute this improvement in both the length and quality of life for CF patients to the fact that there are now more CF therapies than ever before—largely developed with support from the CF Foundation—and even more on the horizon. In addition, the standardization of care and the implementation of “best practices” throughout our care center network is also having an impact.

We will not rest until people are no longer losing their lives to CF. This trend of continuous improvement, however, suggests that we are getting closer to achieving that goal.

For more information, please visit our Web site at [www.cff.org](http://www.cff.org).

## Ask Your Congressman to Join the CF Caucus

The Cystic Fibrosis Foundation has established a bipartisan Congressional Cystic Fibrosis Caucus.



The caucus is co-chaired by two friends of the CF Foundation: Rep. Ed Markey of Massachusetts and Rep. Cliff Stearns of Florida. The mission of the Caucus is to help advance CF-related legislative initiatives. We are pleased to announce that two Representatives from our area, Congressman Howard Coble (R) and Congressman David Price (D) have recently joined. If your Representative has not yet joined, please take the following action:

- First, find the representative for your home address, by visiting <http://www.house.gov>.
- If your representative is not a member of the CF Caucus, write a letter or call your representative and urge him/her to join the Caucus.

**Note:** For your representative to join the caucus, your representative (or their staff) must contact Kate Reinhalter in Rep. Markey's office at (202) 225-2836 or [Katharine.Reinhalter@mail.house.gov](mailto:Katharine.Reinhalter@mail.house.gov), or Chris Leahy with Rep. Stearns' office at (202) 225-5642 or [Chris.Leahy@mail.house.gov](mailto:Chris.Leahy@mail.house.gov).

To learn more about the Caucus and what this means for the CF Foundation, and to find a sample letter that you can send to your representative please visit our Web site at [www.cff.org/legislative\\_action/](http://www.cff.org/legislative_action/). ■

### JOIN CF FOR THE 1<sup>ST</sup> ANNUAL



Saturday, November 4, 2006  
Charlotte Rifle & Pistol Club

We are currently signing up corporate and family shoot teams to participate in this new and exciting event. Enjoy a day of trap and skeet shooting with a down home Southern Barbeque and awards ceremony!

For more information contact Amy Brindley at (704) 321-7852 or [abrindley@cff.org](mailto:abrindley@cff.org)  
**Reserve your spot today!!**

## CFFT Awards \$13.8 Million to CombinatoRx

CFFT and CombinatoRx announced they have entered into a collaboration to discover and develop novel therapeutics built from synergistic drug combinations to treat cystic fibrosis. Under the terms of the agreement, CFFT will award CombinatoRx up to \$13.8 million in research expenses and will also fund up to 75 percent of clinical development expenses through Phase 2a on the first potential product candidate, provided both parties agree to commence clinical development. In addition, CombinatoRx will retain full worldwide commercialization rights, receive payments upon successful completion of certain clinical and regulatory milestones, and own new intellectual property generated during the collaboration. CFFT will be eligible to receive royalties from CombinatoRx on net sales of any approved products.

To learn more about this partnership and to read the article in its entirety, visit the CF Foundation Web site at [www.cff.org](http://www.cff.org). ■

## Search For a Cure

Did you know that you can earn money for the CF Foundation every time you search the Internet? The CF Foundation is now affiliated with GoodSearch.com!

When you need to look something up, just go to [www.GoodSearch.com](http://www.GoodSearch.com) and select the Cystic Fibrosis Foundation as your charity of choice! The site is powered by Yahoo!, so you'll get the same quality search results that you're used to. What is unique about GoodSearch is that it will direct approximately \$.01 to the CF Foundation every click.

Think about how many time we search the Internet each day – those pennies will add up quickly! Other charities have already raised thousands just by getting their supporters to switch to GoodSearch! So please spread the word! ■

## Calling All CureFinders!

As the lazy days of swimming pools, camps and beach trips of summer draw to a close we set our sights on getting to school on time, good grades, sports and, of course, **CureFinders!**

We are excited to announce the CF Foundation's first school and youth fundraising program. This program provides an excellent opportunity to promote awareness about CF in your child's school and in our community and gives him/her the opportunity to be the CF ambassador for their school! Join forces with other families and volunteers across the country to engage students in the fight against CF by raising funds through a simple and fun class competition. The program offers several activities to choose from such as "Change for a Cure" "Jeans Days" and "Jar Wars". Great incentives are offered for the class highest fundraising class, highest fundraising student, and teacher of the highest fundraising class.

Through **CureFinders** we hope to raise \$15,000 minimum, locally and \$1.2 million nationally and it is our sincere hope you will join the CF community in this effort.

Do you think your child's school would like to get involved? Or do you have a friend who's a teacher or has school-age children? It is important to secure participating schools now and get **CureFinders** on school calendars for the 2006-2007 school year, and we need your help! Contact Lori Black today by email [lblack@cff.org](mailto:lblack@cff.org) or phone 704.321.7852. ■



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### Book Recommendation ~ *The Spirit of Lo*, Terry & Don Detrich

**The 20th  
Annual Tennis  
Challenge  
& Ball**  
**October 7, 2006**

benefiting the

Presented By

**Pro/Am Tournament  
Olde Providence Racquet  
Club**

**Black Tie Gala  
Quail Hollow Club\***  
Member sponsors George and Randi Edmiston  
Cocktails, Dinner, Live, &  
Silent Auction

Dancing to the sounds of  
Continental Divide  
\*Til Midnight!

**\*Be a part of the only tennis event in  
Charlotte that brings area pros &  
amateurs together for a day of exciting  
tennis and an evening of fun,  
all for a great cause.**

**Contact the CF Foundation at  
704.321.7852 or [swatt@cff.org](mailto:swatt@cff.org) for  
more information.**