



BLOW AWAY CYSTIC FIBROSIS 2011



Mission Moment Successful Letter Writing Campaigns

Great Strides Team lead, Ashley Bradley composed the letter below to send out to all of her e-mail and Facebook contacts. After sending the letter out on April 15th, she was shocked when she learned that she had already raised \$500 in donations just over the weekend. As of today April 25th, she has raised close to \$2300. Like the rest of us, Ashley is very dedicated to this cause, she is the mother of Lacy, a beautiful and adorable two year old who battles cf everyday.

We encourage EVERYONE to do an online letter writing campaign to fundraise for yourself and your team. It is so easy and just takes a few minutes. Here is Ashley's heartfelt letter asking for donations;

" A day in the life of Lacy...

**6:30 Wake up (usually reluctantly!) *6:40 Eat Breakfast, take 4 capsules of enzymes and vitamins and a laxative in my milk
*7:00 Start the breathing treatment and watch Disney Jr *7:15 Finish Breathing treatment *7:15 Start CPT (chest physical therapy to help loosen mucus) *7:22 Finish CPT 7:25 Get dressed *7:40 Leave for Grand's or DebDeb's (3 days a week, stay at home with Nana the other 2 days) *11:30 Eat Lunch, take 4 more capsules of enzymes *12:30 Take a nap *3:30 Wake up from that much needed nap *4:00 Have a snack and take 2-3 more capsules of enzymes *5:00 Go home and play with Mommy and Daddy for a while *6:00 Eat dinner and take another 4 enzyme capsules and more vitamins and laxative with milk *6:30 Take a bath and brush my teeth *7:00 Play by myself in my awesome pink kitchen while Mommy and Daddy eat dinner *8:00 Start breathing treatments and watch a movie (Nemo, Pinocchio and Tinkerbell are my favs) *8:30 Finish breathing treatment *8:30 CPT for as long as I can stand it *8:40 Go to bed and usually fall asleep before my head hits the pillow!*



May, 2011 Quick Links

- [Register Now!](#)
- [In the News](#)
- [CF Services Pharmacy](#)
- [Become an Advocate](#)
- [Donate Now](#)

Upcoming Volunteer Fundraising Events

May 1st
1st Annual Cruzin' For A Cure Poker Run. 90 mile run around Mobile will include Beer, BBQ and live music for more information contact [Jennifer](#).

May 7th
3rd Annual Great Strides Golf Tournament at Chesley Oaks Golf Course in Fairview. For more information contact [Laura Grandstaff](#)

May 7th
Mt Zion Baptist Church in Aroney, Alabama will be serving BBQ plate lunches for \$10 from 11 am -5 pm for CFF. For more information contact [Marshall Brooks](#).

May 14th
Radneys Body Shop in Anniston will host a Yard Sale

in honor of Trinity Radney and in support of Anniston Great Strides. For more information contact [Kori Saucier](#)

May 21st

5th Annual CF Charity Motorcycle Ride starts at McBride Elementary School in Muscle Shoals and includes food, entertainment and auction. For more information contact [Joyce Mitchell](#)

May 21st

Fishing Tournament in Clanton. For more information contact [Jennifer McEuen](#).

August 4-7

If you are interested in doing a yard sale to raise funds for your team you may want to make it a vacation as well. One of our volunteers is offering to provide the location and room and board for up to 4 volunteers for the four days of the world's longest yard sale event. His 6.4 acre property on Tabor road is 10 miles from the start of the yard sale in Gadsden, Al. For more information contact the [Alabama Chapter office](#).

April 30th Dothan Great Strides

This year has been such an exciting year for our CF patients and families due to the amazing breakthroughs that have occurred with VX-770 and VX-807. We all have so much hope and optimism that a cure will be found much sooner than later. The Foundation has made a commitment to heavily fund this research in order for it to move along at a faster pace, we need to do our part by doing our very best in fundraising for Great Strides. Let's make this a memorable year!

Dothan Great Strides is scheduled for Saturday, April 30th! Our goal for this year's walk is \$19,000 and everyone has been very busy fundraising for the last few months. Special thanks to the 2011 Great Strides Committee who has been very hard at work recruiting Corporate Sponsors and Teams to help us to achieve our goals and raise money for this great cause. Please keep in mind that individuals and teams can still register and fundraise until December 31st, 2011.

If you're keeping track that's 2 breathing treatments that total over an hour with CPT. And 15 capsules for enzymes with meals and that does not include any smaller snacks I might have throughout the day. This may not seem like a lot, but I'm only 2 years old and have been doing this since I was 3 months old. I also get to see the doctor every 3 months and have to get blood drawn every 6 months (not fun for anyone!!). Not to mention having my parents and grandparents constantly making me wash my hands or wipe my face to help prevent the spread of germs. We also have missed a few trips or visits with family or friends during cold and flu season. A cold could be a terrible thing for me. It usually means antibiotics and sometimes extra breathing treatments (up to 3 a day). And sleepless nights for my parents who worry so much about me and want to make sure I get the best care possible.

But all this could change! Have you heard?!? There are some new drugs being made up by some very smart and compassionate people and these drugs could be the answer. These drugs could mean a longer life for me, which means more time I get to spend with my amazing family and friends. They could mean college, a career, a family for someone whose life expectancy at birth was only 37 years old (my parents are in their 30's!).

We are walking in the Great Strides walk to benefit the Cystic Fibrosis Foundation in Mobile, Alabama at the University of South Alabama track on May 14th to help raise money to make these drugs possible. In case you didn't know, the Cystic Fibrosis Foundation does not get ANY funding from the federal government! None! Zilch! Nada! Which means that it relies on the kindness and generosity of people like you and me to make these miracles come true. Nearly 90 cents of every dollar raised is used for vital CF programs. Please join us in this fight for a cure. Any amount will do and all you have to do is click a little button that says "DONATE NOW". It means absolutely everything to me and my family. And I mean EVERYTHING!

Much Love, Lacy :) "



The walk is going to be a celebration and a reason for everyone to get together to show their support in the fight against cystic fibrosis. We will have some special guests with us on Saturday. The Columbia High School cheerleaders will be cheering on all of the walkers as well as the Azalea Dogwood Maidens who will be charming everyone. Just for fun, we will also feature Zumba demonstrations to warm everyone up for the 3 mile walk. For the kids, we will have an inflatable slide, the heroic firemen from the Dothan Fire Department along with one of the fire engines for the kids and Kirby the Kangaroo will be joining us from Army Aviation Center Federal Credit Union to teach kids how to start saving money.

Speaking of fundraising, I would like to mention our TOP fundraising team who has raised and banked a total of \$2,312 as of today - the Yankee Doodle Team, Team Lead, Jennifer Smith. Jennifer is the mother of 22 month-old, Ethan, who was diagnosed with cystic fibrosis at birth. This is the 2nd year that Jennifer has been involved with Great Strides and she has done an incredible job!

Thank you to in advance to our walk sponsors, Army Aviation Center Federal Credit Union, Southeastern Pediatric Associates, P.A., Knology, and Management Services Network, L.L.C. and to all of our walkers - we could not do it without you!

I look forward to seeing everyone in Dothan on Saturday!

CF Family Education Day 2011 @ Children's Hospital

Children's Health System held a patient education day in February and were kind enough to share the information for those of you who were not able to attend. You can see the presentations from the day at the link below.

The topics of the day were:
· "Let's Rock Cystic Fibrosis" - guest speaker [Emily Schaller](#)
· Research Update - by UAB Research Coordinator(s)
· Real Life with CF - CF Panel
· Insurance/Governmental Health Plan update - Suzanne Respass, VP Governmental Relations, Children's Health System

[CF Family Education Day 2011](#)

This link also connects you to other topics that have been presented by CF Center staff and families including Research updates, Respiratory Therapy Updates, CF Related Diabetes, Patient & Family Perspective on research, State of the Art: MRSA, etc.

CF Foundation Announces Investment to Speed Development of Additional Drugs to Treat the Most Common CF Mutation

April 7, 2011

Today the Cystic Fibrosis Foundation announced the expansion of its collaboration with Vertex Pharmaceuticals for the discovery and development of additional drugs aimed at treating the underlying cause of cystic fibrosis.

The new program will support development of a potential new drug called VX-661, designed to treat people with the most common genetic defect in CF, the Delta F508 mutation. Nearly 90 percent of people with CF in the United States have at least one copy of this mutation.

VX-661 is known as a "corrector" and aims to move the defective CF protein to its proper place at the cell surface. Another corrector, known as VX-809, is already in clinical trials. By developing multiple correctors, the Foundation increases the chances of bringing new therapies to the CF community as quickly as possible.

"This new agreement will further leverage the successful collaboration with Vertex to accelerate the discovery and development of new drugs to treat a wide variety of CF patients," said Robert J. Beall, Ph.D., president and CEO of the CF Foundation. "Given the recent announcement of promising data of other compounds in the CF pipeline, we're optimistic that the CF Foundation is on the right path to fundamentally change the treatment of CF by targeting the cause of the disease."

The Foundation's investment, which will be up to \$75 million over five years, will also expedite the discovery and early development of other new correctors.

"The CF Foundation is widely recognized by doctors, nurses, scientists and those with CF as a driving force in the search for new CF medicines, and we are pleased to further expand our strong collaboration with them," said Matthew Emmens, chairman, president and chief executive officer of Vertex. "The collaboration announced today underscores our commitment to CF and accelerates our efforts to develop new medicines as quickly as possible for people with the most common type of this disease."

With the Foundation's expanded support, Vertex plans to begin a Phase 2 study of VX-661 by the end of 2011 and expects to enroll people with CF who have the Delta F508 mutation.

A Phase 2 clinical trial is underway to test combinations of VX-770 and VX-809 in individuals with two copies of Delta F508 mutation. Data from the first part of this trial is expected in the middle of 2011.

May 14th Mobile Great Strides

It has been a year full of hope for our cf patients and families in regards to the cf research funded by the Cystic Fibrosis Foundation. In order for this to continue, we must all do our part and help raise the funds to finance this very promising research. Great Strides is a GREAT opportunity to get involved!

The Mobile Great Strides Walk is scheduled for Saturday, May 14th at the University of South Alabama Track. We have set our 2011 fundraising goal at \$90,000. At present we have 26 teams who are registered and fundraising for the cause. We are expecting between 150-175 participants at this year's walk.

We are kicking off the day with a Great Strides Tailgate Party starting at 8 am. Teams are encouraged to bring a 10 x 10 tent and "tailgate" for the event. Awards will be presented to the team with the "Best Decorated Tent" and also for the team with the "Most Spirit." Check-in begins at 8:30 am and the walk will begin at 9 am. San Miguel's Hacienda will once again be providing us with some wonderful Mexican food for lunch. We are so grateful for their support and generosity again in 2011.

Great Strides caters to the whole family so we cannot forget the children. We have some new games planned for the kid's area this year and we will also have an inflatable slide for all to enjoy. The Azalea Trail Maids will be joining us in their Southern Belle attire as well as Kirby the Kangaroo from the Army Aviation Federal Credit Union to teach the young ones about the art of managing money.



Feel free to review those as well!

We are so grateful to our 2011 sponsors for the walk: Army Aviation Federal Credit Union, Pulmonary Associates of Mobile PC, San Miguel's Hacienda, AT&T, Abbott Laboratories, Gilead Advanced Therapeutics, and Genentech. Thank you to each and every one of our supporters!

I am very excited about seeing everyone at the walk on May 14th and please take advantage of these last few weeks to do any last minute fundraising and surpass your personal/team goal!

September 24th Orange Beach Great Strides



It is never too soon to start fundraising for walks scheduled later in the year. The 2011 Orange Beach Great Strides Walk is scheduled for Saturday, September 24th, 2011. The walk is being held at the Happy Harbor Marina & Restaurant.

The first annual Orange Beach Great Strides Walk was held last year at The Wharf in Orange Beach. In spite of the oil spill and the rainy weather, we managed to raise \$13,739 for the cause. Special thanks goes out to the 2010 committee chair, Angela Bateman and to the Manager of Live Bait at The Wharf, Karen St. Clair. Both never lost faith in this cause nor me. Another thank you to the Mystical Order of Mirams and two very special members, Shannon Clemmons and Eva Keesee who were responsible for securing a large donation from this local Mardi Gras Association.

We are very excited about the new venue for the 2011 walk, Happy Harbor Marina & Restaurant in Orange Beach. In 2010, Happy Harbor played a large part in the walk. Every year they host an event called PirateFest. In 2010, they were kind enough to hold a silent auction during PirateFest and donate all of the proceeds to the Cystic Fibrosis Foundation. The folks at Happy Harbor were such a joy to work with and the location is so wonderful that we decided to hold the walk there this year in conjunction with PirateFest.

Please mark your calendars and if you are interested in joining the Event Committee, sponsorship or joining a team, please feel free to email me at tmiller@cff.org.

Wanna Help?

Cystic Fibrosis Foundation depends on volunteers to make Great Strides, Swinging Fore A Cure, Bay Area's Finest, and all the events a success. If you would like to get involved in any of these events please contact [Tiffany Miller](mailto:Tiffany.Miller@cff.org). Volunteers, sponsors, donated items and team participation are always needed and appreciated.



"Because of risks to people with cystic fibrosis (CF), individuals with a confirmed positive sputum culture for *Burkholderia cepacia* complex shall not attend this event. This is because *B. cepacia* can be passed between individuals who have CF through close proximity. *B. cepacia* infection in a person with CF can cause serious respiratory illness and, in some patients, may lead to death. Despite this policy, there might still be some individuals with *B. cepacia* in attendance. *B. cepacia* is not a risk for otherwise healthy individuals. For alternative ways to participate and for information about this policy, please contact the CF Foundation at (800) FIGHT-CF or visit our Web site at www.cff.org. Consult your CF care center physician with medical questions."