

Great Strides 2012

Great Strides is the Foundation's largest national fundraising initiative. A year round campaign which culminates with celebratory walks in May and June, Great Strides is truly the key to helping "blow away CF." We hope you'll join us for what promises to be an exciting and successful walk season.

Sign Up for a "Sign Up"

Are you proud of your Great Strides walk team? (you should be!) Do you want everyone to know what a fantastic team you have? (of course you do!) Would you like your team to feel extra-appreciated on walk day? (who wouldn't want that?) Then you'll love this fun incentive that will inspire you to register your team and start your fundraising off on the right foot.

Register your team and have five registered, fundraising walkers* by February 10, 2012

and your team will have their very own sign up at this year's Great Strides walk.

You and your team will be able to design a sign (with your team name, a

picture, whatever you would like) and we'll have it printed and brought to the walk for you. This is a great chance for every team to shine like super stars on walk day.



Registering is easy—simply visit our website at <http://detroit.cff.org/greatstrides>. There are some great new features on the site to help you with your fundraising, including new social media tools.

So hurry over to the site, register your team and have your walkers start fundraising so you can earn special recognition at this year's walk!

If you have any questions or need help registering feel free to contact us at (248) 269-8759. We're always happy to help!

*Registered walkers who have money banked

Inspiration Station

What's Your Intention?

Some days I lace up my running shoes, excited for the day's workout, ready to move, knowing that my run is going to be great. Other days I sluggishly pull my shoes on, wishing the workout were over before it even begins. The interesting thing is, the way I start my run is usually how I end my run. It's really all about the intention I set at the start of the workout. If I expect it to go well, it almost always does.

And it's not just for my workouts—it's the same for my job, my family and friends, my chores around the house and, yes, even my fundraising. When I intend to put in a full effort, I reap full rewards but if I decide to do anything with half a heart, I end up with half hearted results.

As you head into this new season of Great Strides, take a few minutes to ask yourself what your intention is. Are you sending out a basic letter to friends and family hoping for a few donations? Or are you writing a great letter and sending it out expecting that others will be inspired to give? Are you thinking you might be able

to raise the same amount as last year? Or are you setting your goal a little higher, knowing that your passion for the mission will help you achieve that fundraising goal?

So, go ahead and set your intentions to have a successful Great Strides season. Intend to take the ups and downs with a positive attitude. Don't sluggishly approach your fundraising, hoping to simply get it over with. Expect great things from your fundraising efforts then watch as great things happen.

-Mary Ellen Kearney, newsletter editor

Wrap It Up

Success Stories from NEW Great Strides Wrap Events

Wrap events—events put on by volunteers to raise funds for their Great Strides team goal—are an integral part of the Foundation's efforts to find a cure for CF. We're excited to share some of our volunteers most recent successes with these stories about new events that happened this fall.

Victory for Violet Turkey Trot

New team leader, Bonnie Ash, sprung into action to fight CF right after finding out her newest granddaughter, Violet, had been diagnosed with CF. "We gathered a group of family and friends and had our first fall fundraiser on November 20th, titled **Turkey Trot** at Woodlands Park in Perrysburg, Ohio. Friends, family, and coworkers attended the ¼ mile family walk and scavenger hunt to find pinecones, bird feathers, turkeys, pumpkins, and much more. The children were entertained with

an array of Thanksgiving crafts to make as keepsakes. Apple cider and donuts were served to all in attendance. Through our admission charge, the 50/50 raffle, and generous contributions of those in attendance, we raised close to \$5,000 for our team, **Victory for Violet**, to help fund research to cure this horrible disease."

Crystal's Crew Spaghetti Dinner

Crystal Webert, CF patient and dedicated team leader, decided to expand her fundraising efforts this fall with her first spaghetti dinner. More than 100 people attended the event enjoying great food, fun, an entertaining dj and a spectacular silent auction. Crystal's father gave a wonderful speech where he talked about the ways CF affects the lives of patients and helped educate those in attendance about CF and why we need a cure.

Crystal and her team are already excited to start planning their second annual spaghetti dinner to take place in 2012 and hope to raise more than the \$10,000 they raised for their 2011 team.

Team Aiden's Chili Cook—Off

The Birch Run community knows what fall Saturdays are made for—chilli cook offs! Over 100 people attended this first year wrap event to enjoy delicious chili and bid on over 75 silent auction items. The event, hosted by Mark and LeAnn Stein, took place at the Gateway Sportsman's Club in Unionville, MI and raised over \$4000. Special thanks to Vadavilla Adult Care Center for generously sponsoring this year's event. This event was a great reminder of how amazing things can happen when a community comes together to support a cause.

Upcoming Events

Our volunteers are awesome! Check out these great wrap events scheduled for this spring*.

Saturday, February 4, 2012 – **The 25th Annual Cystic Fibrosis Dinner and Auction Benefit** – ZCJB Hall – Owosso, MI
Contact Erika Tyrell at (517) 795-0492 or rturtlepwr@aol.com for more information.

Saturday, February 25, 2012—**Cystic Fibrosis Benefit Spaghetti Dinner**– Flushing Moose Lodge
Contact Adrian at alaux@cff.org or (248) 269-8759 for more information.

Sunday, February 26, 2012, 11:30am-1:00pm —**Carson's Crew and Kennedy Too Spaghetti Lunch**—
Woodville United Methodist Church Salad, spaghetti & meat sauce, garlic bread, dessert & drink. Freewill offering.
Contact Shelly at sfranics@cff.org or (248) 269-8759 for more information.

Saturday, March 3, 2012, 6:30 PM - **Winter Beach Blast** – Washtenaw Farm Council Grounds
Visit www.cfpartyforbreath.com for more information or to purchase tickets.

Sunday, March 25, 2012—**Rock CF Rivers Half Marathon**– Grosse Ile High School
Visit www.outrunfcf.com for more information or to register.

April 2012 (date to be determined) **Sal's Pals 10th Annual Dinner and Auction**.
Please check Sal's Pals website at www.salspals.com

Have an event coming up? Please email Adrian at alaux@cff.org with information regarding your event and we'll do our best to spread the word on Facebook and in our monthly email.

We encourage our volunteers to fundraise year round for their Great Strides teams. Talk to your staff partner any time for help in creating a great game plan to reach your fundraising goals.

Research Update

High Priority

Funding research has always been a top priority for the Cystic Fibrosis Foundation and we've recently had some major news to report. Read on to see what's been happening and why it is more important than ever to continue funding this research.

Have You Met Kalydeco?

In late 2011, Vertex Pharmaceuticals, Inc., announced that the U.S. Food and Drug Administration (FDA) has granted a request for a six-month priority review of a potential new CF therapy, Kalydeco™, formerly known as VX-770.

If approved, Kalydeco (pronounced *kuh-LYE-deh-koh*) would be the first drug available that targets the underlying cause of CF.

Vertex is seeking approval of the drug for people ages 6 and older with the G551D mutation of CF.

The expedited review sets a target date of April 18, 2012, for the FDA's approval decision, four months earlier than the standard review time of 10 months.

The FDA grants priority review status for several reasons — for example, if a potential drug is considered a major treatment advance.

Kalydeco was discovered in a collaboration between Vertex and the Cystic Fibrosis

Foundation that began more than a decade ago, with the Foundation providing substantial scientific, financial and clinical support throughout the development process.

The FDA application follows the release earlier in 2011 of groundbreaking results from late-stage clinical trials of Kalydeco in people ages 6 and older with at least one copy of the G551D mutation of CF. Study volunteers who received the drug showed significant improvements in lung function, weight gain, pulmonary exacerbations and sweat chloride levels.

But Wait, There's More!

As part of its effort to speed the development of therapies targeting the basic defect in CF, the Cystic Fibrosis Foundation has entered into a collaboration with Pfizer, Inc., one of the world's largest pharmaceutical companies.

The goal of the program is to discover compounds to treat people with the most common CF mutation, Delta F508. In this mutation, the defective CFTR protein does not fold in the correct way to reach its proper place at the cell surface, where it helps maintain the proper flow of salt and fluids into the airways.

Nearly 90 percent of people with CF have at least one copy of the Delta F508 mutation.

The new agreement grows out of an earlier collaboration between the CF Foundation and the biotech company FoldRx Pharmaceuticals, Inc., which Pfizer acquired in 2010.

"This collaboration marks a very exciting step in the fight against CF," said Robert J. Beall, Ph.D., president and CEO of the CF Foundation. "Pfizer's commitment of resources and scientific capacity, combined with its expertise in the field of rare diseases, will help accelerate the development of more therapies targeting the underlying cause of CF that will benefit the greatest number of people with the disease."

Pfizer has significantly expanded the team of scientists and technicians working on the CF program, and will also be able to draw on its massive library of about 5 million chemical compounds to screen for potential CF therapies.

We're On the Right Path

As you can see, we're making big moves in the fight against CF and we're excited to continue bringing new research to the table—research that we hope will change the lives of those with CF. We're so thankful for wonderful fundraisers and donors who are helping to keep us moving in the right direction.



Get ready to out run CF!

Sunday, March 25, 2012

Join the Rock CF Foundation's dream to Out Run Cystic Fibrosis! This 2nd Annual Half Marathon, Half Marathon Relay & 5K Run/Walk is your chance to support cystic fibrosis research, raise much needed awareness and get in a healthy dose of running.

Proceeds from this event support the Cystic Fibrosis Foundation .

For more information or to register please visit <http://www.outruncf.com>

A Fantastic Fall

Each fall the Cystic Fibrosis Foundation presents several fundraising events. These events envelope a range of interests and are a chance to engage members of the community in the mission of the Foundation. While fall 2011 demanded a lot of hard work we are pleased with the successful results of many of our events.

The Fourth Annual Shoot for a Cure

Overcast skies provided the perfect backdrop for this year's Shoot event which took place on September 28th, at the Detroit Gun Club. Teams, once again, gathered together to, literally, take their best shot at winning the traveling trophy at this fun filled day, featuring a sporting clay tournament. Once the guns were racked and the shooting scores were tallied, **Team Roush**, came out on top and will have bragging rights until September 2012. Shooters were inspired by guest speaker, CF patient Ryan Schroeder, and gave generously from their wallets. With the help of many wonderful sponsors this event exceeded all expectations and raised over \$38,000. The event committee already has the 2012 event "in their sights."



Shooters make their way to the next station at the Shoot for a Cure

The Eighth Annual Lansing Area Wine Opener

It's no surprise that this year's Wine Opener was a success. Guests gathered together at Eagle Eye Golf Club on October 20th, for a delightful evening. The cuisine, from local area restaurants, was outstanding and the perfect companion to the many featured wines from all over the world. The silent auction featured items for the most discerning of tastes and the live auction featured great packages, including a chance to see the Spartans take the field in the Outback Bowl. Special guests included Tom Izzo, Suzy Merchant, Mark Hollis and Jake Boss, making the evening extra special for all the MSU fans who were in attendance. The Lansing community once again showed their commitment to making a difference as seven wonderful sponsors stepped up, including four brand new sponsors for 2011. The support of these wonderful sponsors and the generosity of all who attended helped us bring in over \$33,000 for the fight against CF.

Special Thank Yous

A very important thank you to our wonderful event committees for their continued support of and dedication to the Foundation. Without these committees, who often go above and beyond, we would not have been able to hold these wonderful events.

Shoot for the Cure Committee

Dean Massab
Andy Wozniacki
Mark Slack
Scott Schueller
Chris Masters
Steve Whalen
Ali Maher
Paul Geiser



Guests at the Wine Opener were greeted with a glass of champagne and a beautiful arrangement of 65 Roses.

Lansing Wine Committee

Honorary Chair: George Perles
Carmen Argersinger
Mike Brenton
Rachel Freund
Lana Huntoon
Tami Jackard
Maggie Upson
Nort Upson
Rajeev Patgaonkar
Gary VanDam
Bobby Popp

Thank you to our outstanding sponsors.

Shoot for the Cure Sponsors

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Lansing Wine Sponsors

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Dean Transportation
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Strathmore Development Company

Southeast Michigan's Finest



Southeast Michigan's Finest event is a wonderful event which gives individuals in our community a chance to shine as they show their support for the Cystic Fibrosis Foundation. Individuals who are nominated for this event are asked to fundraise a minimum of \$2500 over a six week period. At the end of the six weeks the honoree who has raised the most money is named "Southeast Michigan's Finest."

We'd like to give a special thank you to the 2011 honorees-

Mr. Christopher Zahorec
Mr. Bryan Johnson
Dr. Ruma Srivastava, M.D.

This year brought a very close competition amongst the honorees with first and second place being separated by a few dollars. This year's winner was Mr. Bryan Johnson who brought in \$7,970. The dedication of all of our honorees should be commended. These individuals all remind us that taking time to make a difference can be a part of anyone's life.

Mr. Bryan Johnson

Bryan Johnson is Manager of Marketing and Communications for ZF Group North American Operations. He is responsible for all marketing and communications efforts within the North American region including advertising, product imaging, public relations, trade shows, crisis management and corporate communications.

Johnson joined ZF in 1999 as a marketing assistant. He also held the position of Marketing Manager – Automotive, where he handled

automotive trade shows and automotive product imaging.

As an active member of the automotive community he serves on the Communication Executive Council for the Original Equipment Supplier Association and is a member of the Automotive Press Association, Automotive Public Relations Council, and the Society of Automotive Engineers.

He actively supports the Cystic Fibrosis Foundation through Sauber's Strength a Great Strides team founded to honor his niece and nephew who both have CF.

He earned a bachelor's degree in business administration from the University of Toledo in Toledo, Ohio, where he was a member of Pi Kappa Phi Fraternity. He is a resident of Canton, MI, with his wife Anna.



Southeast Michigan's
Finest,
Mr. Bryan Johnson

More Fall Events

Run Like Hell 5k

In its second year, the Run Like Hell 5k was a spook-tacular treat for those interested in celebrating Halloween and supporting a great cause. Participants, many dressed in costume, took to the streets of Ferndale for a moonlit, evening race. This year's event began and finished at "The Loving Touch," a bar and pool hall, where participants enjoyed tasty post-run snacks and a refreshing beer. This event brought together runners and walkers alike for a great cause.

Moonlight and Martinis

This year's event experienced a refreshing change of venue as the CFF took over the second floor of Tin Fish in Novi. Guests were greeted with delicious hors d'ourves and several martini tastings. Everyone seemed to find an item in the silent auction worth bidding on. The evening was a hit and guests made it clear that they enjoyed themselves by staying until the very end of the evening.

Cooking for a Cure

Garber Automotive Group and Horizons Conference and Event Center

put on the first annual, *Cooking for a Cure* in Saginaw, Michigan on Thursday, October 27, 2011. The event consisted of delicious food tastings from eleven of the area's finest restaurants, cocktails, live entertainment and a tin can auction with wonderful items ranging from Michigan Football tickets, to a handmade Adirondack chair, to fine jewelry. There was a short presentation recognizing corporate sponsors and explaining the effects of cystic fibrosis. Nearly 250 people attended this first-time event which raised \$27,436 towards a cure. We are looking forward to the second annual event this year!



Find us on Facebook

Looking for an easy way to stay connected and find out what's going on here at the CFF? Be sure to check out and "like" our chapter Facebook page.

We're easy to find now that we have our very own URL. Just visit www.facebook.com/CFFMetroDetroit

Tell your friends to "like" us too!

Did You Know?

You can help fund the mission of the CFF by donating stock. We've recently received two generous stock transfers from wonderful donors totaling \$28,000. Think of the Research we can fund with that! If you're interested in donating stock please contact any staff

member at (248) 269-8759.



More Ways to Get Involved

Join an Event Committee

Well functioning committees are the key to successful events here at the CFF. Every event we hold, including Great Strides can utilize the help of a strong committee—and that's why we need YOU! Regardless of your skills or where your interests lie we have a spot for you. All you really need is the desire to make a difference and help us make our events successful. If you are interested in learning about committee positions for any of our events, please contact Shelly Francis at (248) 269-8759 or sfrancis@cff.org

Auction Items

Have you ever seen one of our live or silent auctions? We've had some pretty amazing items over the years but we always have a need for more—whether it's tickets to a sporting event, a piece of jewelry, gift certificates to local restaurants or a stay in a luxury hotel. We're always on the lookout for potential items. If you are interested in helping us secure auction items or if you have items you would like to donate to be included in one of our upcoming auctions please contact Adrian Laux at

(248) 269-8759 or alaux@cff.org

Fundraising Tips (From REAL Fundraisers)

Here are a few tips on different ways to succeed from Great Strides team leaders in our area.

Detroit team leader, **Anna Monaghan**, created a video of her son, Liam, showing what he goes through each day dealing with CF and letting people see who he is—a great kid who loves the color orange. She sends this video to everyone she knows and asks them to pass it along, it's a great way to connect people to the real reason she's fundraising. Anna says "I know it feels good to friends and family who are glad to have a positive and effective way to show their support. Complete strangers have even heard our story and gotten involved."

Carol Smith, CF grandma and team leader at the Tri-City walk reminds us to "send your letters out early to supporters." Not only does this give your donors plenty of time to respond but it also gives you a chance to follow up as you get closer to your walk. The earlier you start, the more time you have to reach your fundraising goal.

CF patient and team leader, **Emily Schaller**, suggests changing the message you send to your potential donors. "I would say using the news of the new drugs and treatments as a way to show the donors where their money is going is key. Maybe take a step back from focusing on how you or your child is doing, but instead focus on

how a new treatment that was developed with the help of fundraising is changing the life of someone else living with CF."

Our final suggestion comes from **Cathy Wood**, Rochester team leader. "Check with your company if they have matching contributions, they could double your donation! Also, if you have team members that are soliciting, make sure they note it in their letters as well." Not sure if a company offers matching gifts? Visit <http://www.matchinggifts.com/cff/> to find out.

Thanks to everyone who shared a tip—we hope these will encourage you to think outside the box for your own fundraising.