

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 17, 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://www.cff.org/Chapters/grand-rapids/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 (616) 956-6850. 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

Fourth Annual Tee-Up for CF Golf Event



Boulder Creek Golf Club was the site of the Fourth Annual Tee-Up for CF Golf outing. Thank you to all those that came out and helped the CF Foundation raise an event record of \$13,000.

Congratulations to the winning team Drajka who joined more than 20 other foursomes for this event. Golfers enjoyed freshly made omelets from Eggland's Best before a sunny day of golf that included amazing food from 7 Bite

Sponsors as well as challenges from Hole Sponsors and even had an opportunity to win \$10,000.

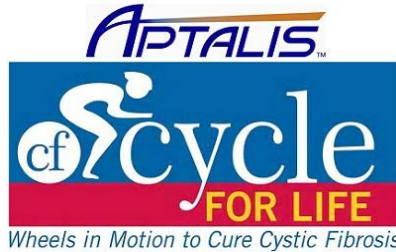
Our appreciation goes out to all of sponsors, volunteers and the golf course for their hard work. We are excited for 2012 and already preparing plans for the Fifth Annual event!

Participants from all over the region turned out and enjoyed a perfect riding day in Holland. Riders arrived in the morning at the Howard B. Dunton Park in three stages, depending on their choice to ride the 65 mile route, 35 mile route or 15 mile route.

Riders were cheered on along the way and celebrated their return with great music and plenty of food.

We want to thank all of the participants for their fundraising efforts and kind feedback! Also, thank you to our volunteers for all of their hard work and great energy in helping make this event a success.

Cycle for Life



On Sunday, September 18th 2011 the Cystic Fibrosis Foundation held its Annual CF Cycle for Life.



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>

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.





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.

Find us by searching for "Cystic Fibrosis Foundation Greater Michigan"

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 us at (616)956-6850.



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 Rob Powell at rpowell@cff.org or (616) 956-6850.

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 real Great Strides team leaders.

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 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**, Great Strides 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.