

GMW Chapter News Footnotes 2009



Cystic Fibrosis Foundation Greater Michigan West Chapter

CF Foundation continues to make advancements in science and CF Care. An update from Dr. Beall

The Foundation continues to earn world-wide recognition for our success developing new CF treatments, advancing quality care and furthering the search for a cure.

This summer we continued to achieve progress in key areas. Here are some highlights:

- Phase 3 VX-770 trials are underway, including studies of the treatment in patients with the G551D mutation, the F508del mutation and patients as young as six years of age. In addition, the VX-809 Phase 2 trial is now recruiting patients and, as you may remember, this drug could potentially be effective in over 90% of the CF patients that have the F508del mutation.
- Two additional Phase 3 trials directed toward treating the basic defect are underway. PTC Therapeutics just launched its Phase 3 trial of Ataluren (formerly known as PTC124). Inspire Pharmaceuticals has nearly completed enrollment of its Phase 3 trial of denufosal. Inspire is aiming for FDA approval of this therapy in 2011.
- Nearly 250 patients have received help with their drug co-pays through the new CF Patient Assistance Foundation. The fact that over a quarter of our patients skip some of their treatment because of financial concerns underscores the need for this important, industry-supported program.
- The Foundation received its second 4-star rating from Charity Navigator for exceptional fiscal management. This recognition is a tribute to the entire Foundation and its focus on innovation and efficiency.

In addition, we estimate that over 13 Phase 3 trials may be completed by 2013. When you consider that in the past 15 years only two drugs have been approved by the FDA, we must be excited by our progress.

Our greatest achievement by far is that those with CF are living longer and healthier lives.

GREAT STRIDES 2010—Did you know?

- CFF Staff start planning for the GREAT STRIDES 8 months out?
- More people donate more money online than by writing a check or giving case?
- You can fundraise for your GREAT STRIDES team until December 31?
- GMWM Chapter has more participants for GREAT STRIDES than ever before?
- Your involvement with GREAT STRIDES planning is crucial to each year's success

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65 Roses Bike Tour 2010

Do you ride? Do you know people that ride? Help plan the new 65 Roses Bike Tour in 2010.

If interested, contact Jay Simon at:
PH: 616-241-2100
Email: jsimon@cff.org



6th Annual Wine & Roses for Cystic Fibrosis

The 6th installment of Wine & Roses will feature a diverse menu that will make your palate dance. The menu will have exceptional tastes from **Smokey Bones Bar & Fire Grill, Bar Divani, Shogun, Papa Vinos, The Melting Pot, and the Spinnaker.**

Will the Riesling or Merlot be your favorite? There will be a fantastic assortment of wines provided by **Constellations Wines** for you to sip, savor and to discover. Along with the great wines, guests will be able to enjoy beverages from **Bacardi** and **Martini & Rossi**. Coffee will be provided by **Biggby Coffee**.

Even if it is cloudy, the stars will be out on Friday, October 16, 2009 at the Hilton Hotel in Grand Rapids. Celebrities from West Michigan will be on hand serving drinks and food and making sure you have a great time. Wine & Roses is a great way for you to get to know your favorite West Michigan celebrity.

Fantastic jazz music and live and silent auctions will add to an already unbelievable evening. A general admission ticket for Wine & Roses is \$80.00 (\$60.00 of which is tax-deductible) and includes admission to the event, all food and wine tasting and a keepsake tasting glass and journal. To purchase tickets or a corporate table, please go to <http://grand-rapids.cff.org/wineandroses09> or call the Cystic Fibrosis Foundation at 616-241-2100.



How Many Steps Would you Take for a CURE?

Join The Grand Rapids Police Department, The Grand Rapids Fire Department, Puddin from WSNX 104.5 fm and many others as we climb 565 Steps, 22 Floors, to reach 1 Goal—a cure for cystic fibrosis



The Inaugural Climb for a Cure will be held Saturday November 7, 2009, 10:00 a.m. at the BRIDGEWATER PLACE (free parking) in downtown Grand Rapids. This challenge with over 500 steps, promises to be an amazing event for competitive and non-competitive climbers alike. Whether you form your own team or climb on your own, each step you conquer will bring us closer to finding a cure for cystic fibrosis.

Participants can register online at <http://grand-rapids.cff.org/stairclimb09>

Climb for a Cure Committee Members;
 Lt. Wayne Wu - Grand Rapids Police Department
 Sally Tucker - Signature Associates
 Ed DeMaagd - Grand Rapids Fire Department, IAFF Local 366
 Lisa - Nye Uniform, The Playhouse WSNX 104.5 FM

MURDER MYSTERY

a Cystic Fibrosis Foundation Fundraiser

Put on your costume, get out your masquerade mask, grab your magnifying glass and prepare to spend the evening solving a mystery. The Cystic Fibrosis Foundation is hosting their second annual Murder Mystery Fundraiser.

Join us the night before Halloween for **MURDER AT THE MASQUERADE...a murder masked in comedy**

It's the night before Halloween and the party was to die for. When the clock strikes murder which guest is disguised as a killer? It will be your job to play the part of Detective in this interactive, comedy-mystery that's sure to be a scream.

Event participants will enjoy social and networking time, a theatre performance, dinner and auction featuring masks created by local artists.

Costumes/Masquerade masks are encouraged but optional.

Individual tickets are \$65.00 or \$110.00 for a couple. Corporate tables and sponsorships are available. Tickets can be purchased online at <http://www.MurderAtTheRadisson.com> or by calling 616-241-2100.

Cystic Fibrosis Scholarship Foundation

Helping young adults with CF pursue their dreams

The Cystic Fibrosis Scholarship Foundation (“CFSF”), founded by a parent of a young adult with CF, is pleased to announce a scholarship program for students with cystic fibrosis. CFSF is not part of nor is it funded by the Cystic Fibrosis Foundation. The program is available to those who will be enrolled in an undergraduate college program or vocational school in the fall 2010.



Scholarships will be awarded based on a combination of financial need, academic achievement, and leadership. In the past, approximately 25% of the students who apply have been awarded scholarships. Awards may be used for tuition, books and room and board. Awards will be sent directly to the institution that the student is attending. Both multi-year awards and single year scholarships are awarded. Most awards are for \$1000.00 per year. All high school seniors will automatically be considered for the Kevin Tidwell Memorial Scholarship and the Glen Parsons Memorial Scholarship with is a \$10,000.00 award (\$2500.00 per year). Students granted a single year award may apply in subsequent years for further awards although there is no guarantee of future awards. Multi-year award recipients must maintain a 2.0 grade point average or above to maintain their scholarship and continue to be a full time student. All students will be considered for both the multi-year and single year awards.

Recipients of awards will be notified by April 20, 2010. Scholarship applications forms will be accepted after January 15, 2010 and are due to the Foundation by March 21, 2010. Application forms are available via email to MKBCFSF@aol.com , or by phone by calling 847-328-0127. The application forms are also available at the website: cfscholarship.org. Applications for the 2010-2011 school year will not be available until early November. When requesting an application please indicate your current status in school (i.e. high school senior, freshman in college, etc.). This is important in order to be able to send the appropriate application form.

155 Sherman Ave., #116 Evanston, IL 60201, 1-847-328-0127, Email: MKBCFSF@aol.com, Website: cfscholarship.org

CF Foundation Provides Guidance on Seasonal and H1N1 Influenza

The CF Foundation is closely monitoring the seasonal and H1N1 (swine) flue situation. The Foundation recommends that all people with cystic fibrosis and individuals living with them follow the recommendation of the Centers for Disease Control and Prevention (CDC) on both seasonal and H1N1 flue prevention and vaccination.

Based on the CDC's recommendations, the Foundation urges everyone with CF and those who live in the same household to:

1. Get the seasonal flu vaccine as soon as possible.
2. Get the H1N1 vaccine when it becomes available in October.
3. Minimize the spread of germs by:
 - Washing your hands often with soap and water or alcohol-based hand gel.
 - Using a tissue when coughing or sneezing, then washing your hands.
 - Avoid touching your eyes, nose and mouth since germs are spread that way.
 - Staying away from others if you are ill.

Seasonal and H1N1 Flu Vaccines

The seasonal flu vaccine is an important step in protecting against seasonal flu. Vaccination is especially important for people at high risk of serious flu complications, such a people with CF.

The seasonal flu vaccine **will not** protect you against the H1N1 flu. A new vaccine against H1N1 flu is being developed. The CDC states that the vaccine will be available in October. **People at greatest risk for H1N1 flu – such as those with CF – should receive the H1N1 vaccine as soon as it is available.**

Vaccinations for people with CF are available at CF care centers. Household members of people with CF also should receive the seasonal and the H1N1 flu vaccinations. The best way to protect against seasonal and H1N1 flu is by practicing good infection control. For more information on infection control or vaccinations, talk to your CF doctor.



...adding tomorrows every day.

Cystic Fibrosis Foundation Greater Michigan West Chapter

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"Adding tomorrows everyday"

[WWW.CFF.ORG/
CHAPTERS/GRAND-RAPDS](http://WWW.CFF.ORG/CHAPTERS/GRAND-RAPDS)

[WWW.CFF.ORG/
GREATSTRIDES](http://WWW.CFF.ORG/GREATSTRIDES)

The Mission of the Cystic Fibrosis Foundation, a non-profit donor supported, organization is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease.

2009 CF Foundation Calendar of Events

October 16—6th Annual Wine and Roses for Cystic Fibrosis—Grand Rapids, MI

October 30—2nd Annual Murder Mystery Dinner—Kalamazoo, MI

November 7—Inaugural Climb for a CURE—Grand Rapids, MI

November—Volunteer Dinner

Do you have an hour or two?

Our chapter is looking for volunteers to spend an hour or two per week in our office.

As a volunteer you would help with many duties, which may include: filing, contacting companies for auction items or donations, answering the phone, calling volunteers, and preparing office for special events.

If you are interested and have an hour or two per week, we would love to have you. Please contact Jay Simon or Danielle Robinson at 616-241-2100.

Who is your CF Foundation Staff Partner?

Do you have questions about GREAT STRIDES, the website, setting a fundraising goal, or need ideas to get your fundraising underway? Your GREAT STRIDES partner is available to help you with anything you may need for your walk team and fundraising efforts.

Jay Simon

Executive Director

Holland GS, Grand Haven GS, Muskegon GS, East Jordan GS

Wine & Roses For Cystic Fibrosis

Stair Climb

65 Roses Bike Tour

Email: jsimon@cff.org

Phone: 616-241-2100 or 800-968-1050

Danielle Robinson

Director of Special Events

Greenville GS, Edmore GS, Kalamazoo GS, Grand Rapids GS, St. Joseph GS

Golf for a Cure, Tee Up for CF, & CFF Celebrity Golf

Murder Mystery

Email: drobinson@cff.org

Phone: 616-241-2100 or 800-968-1050