

CFF

Friends of the Foundation

CYSTIC FIBROSIS FOUNDATION FALL 2008

BEF Nebraska Golf Classic

The Nebraska Golf Classic, a banquet and golf event, took place on July 17 and 18. The event began with a VIP reception, during which keynote speaker Jerome "The Bus" Bettis autographed pictures for attendees. The festivities then moved to the Windsor Ballroom in the brand new Embassy Suites La Vista. This was the first charity event to be held in the venue, making it an even more special and memorable occasion.

Nearly 600 guests mingled, bid on silent auction items, and sampled the various drink stations, serving everything from martinis to wine to cognac. The live auction, which took place following dinner and Mr. Bettis' keynote speech, allowed attendees access to events and experiences that are generally unavailable to the public, including a tour of ESPN studios, tickets to the Home Depot College Football Awards Show and Ryder Cup access.

Beautiful weather, celebrity golfers, and exceptional food set the tone for the golf outing held at Quarry



NFL great Jerome "The Bus" Bettis challenges the audience at the BEF Nebraska Golf Classic banquet to do their part to help others.

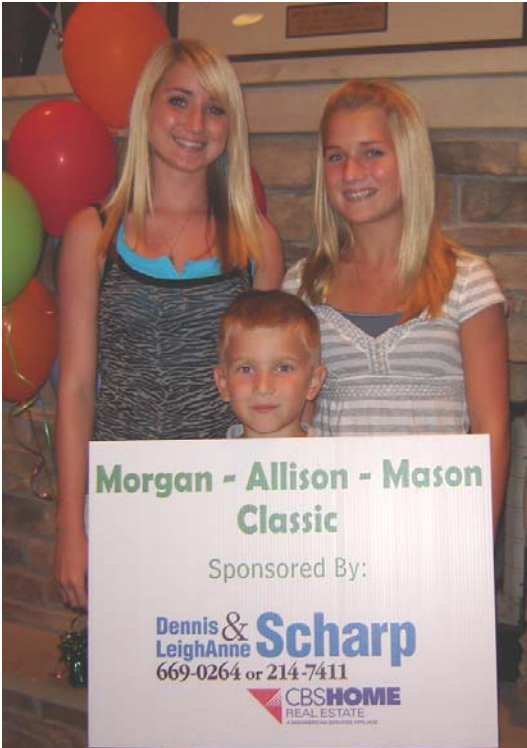
Oaks the next day. After a complimentary breakfast and a few shots on the driving range, the tournament began. To enhance the experience of regular play, golfers had opportunities to buy into a tournament-wide poker hand and take advantage of the skills of golf pro Ryan Nietfeldt on the 10th hole. The men and women enjoyed beverages, burritos, crab cakes, and sashimi while playing the picturesque course. After 18 holes, they made their way inside for post-play massages, dinner provided by Old Chicago, and an awards ceremony.

Continued on page 2...

VERY SPECIAL THANKS

to our Presenting and Celebrity sponsors:

SONY - TRAVEL & TRANSPORT - TD AMERITRADE - CHILDREN'S HOSPITAL



Morgan, Allison, and Mason with a hole sponsor sign from the Golf Classic in their honor.

Morgan-Allison-Mason Golf Classic

As young children, Morgan and Allison were happy little girls who struggled to gain weight, despite the enormous amount of food they ate. They also suffered from frequent coughing and lung infections—yet they played as normal kids and took their frequent bouts of illness in stride.

In January of 2000, Allison (then five years old) was referred to a sinus infection specialist. The specialist found nasal polyps, which are never seen in children—unless they have cystic fibrosis (CF). Just before their 8th and 6th birthdays, Morgan and Allison were tested for CF—and their lives changed forever with both of their diagnoses.

The decision to have a third child is hard for any family. This decision carried a huge risk for Morgan and Allison’s parents, as gambling with genes posed the 25 percent possibility of another child suffering from the disease. In October of 2001, they were blessed with a precious baby boy, Mason. He tested positive for CF ten days later.

On Saturday, August 16th, the second annual Morgan-Allison-Mason Golf Classic was held at The Players Club at Deer Creek. With over 70 people in attendance, the golf tournament built awareness for the disease while raising over \$3,000 for the Cystic Fibrosis Foundation. It proved to be a beautiful day on the course, followed by a fabulous dinner and reception. In addition, a few lucky participants went home with wonderful prizes, including golf for four at Ironwood Golf Club, a \$300 spa package from Reaction Day Spa and a Canon camera, to name a few.

We extend our sincerest gratitude to our hole sponsors, donors and golfers. It is because of their generosity that we know we will find a cure for CF in Morgan, Allison and Mason’s lifetimes. We look forward to seeing you all at the 3rd annual Morgan-Allison-Mason Classic in 2009!

Contributed by Chastin Bailey

...BEF Nebraska Golf Classic, continued from page 1.

Participants consistently described this year’s event as “excellent.” From the Nike Player’s Package to the banquet facilities to the auctions, they indicated their enthusiasm about taking part in the event next year. In addition to having had an enjoyable experience, several attendees expressed their appreciation of those who told stories and shared personal experiences of living with cystic fibrosis. Sixteen-year-old Candace Carlson delivered a poised and profound speech about the challenges of school, playing sports, and maintaining friendships—and doing so with CF. CF father Leon Thomas provided a different perspective, emphasizing the medical advancements that are helping children with CF, like his son, Alex.



Golfers enjoying the course at Quarry Oaks in Ashland, NE.

The event surpassed its fundraising goal, netting \$225,000 for disease research. *Contributed by Melissa Smigelsky*



Dee Acquazzino, CF Peds Clinical and Research Coordinator, Nebraska Regional CF Center

Nebraska Regional Care Center Update

Fall is a busy time at the CF Center. Our younger patients and families are getting back to the school routine, and many of our adults are heading off to college—all of which can be challenging for those with special health considerations—but definitely worth the effort.

Our staff is always excited anticipating the North American CF Conference held every year in October! More than 15 of our CF team will be able to participate in the conference this year, which will be held in Orlando, FL, October 23-25th. Researchers and clinicians from around the world gather to present the latest in CF research, medications and therapies. It is a great time to learn more about the amazing research that's been accomplished over the year and also gives us an important opportunity to network with other CF teams to discuss ways to continue to improve the care we provide to our patients.

This conference is sponsored and organized by the Cystic Fibrosis Foundation. It is impossible to come back to work and not feel inspired and motivated after this conference and see that the dollars raised by the Foundation have made this research possible. Our team is humbled to be in the presence of these researchers, knowing that they are helping us to better understand CF and developing treatments that make life easier and longer for each and every person with CF. We will be anxious to share what we learned in future newsletters and educational forums.

Thank you for your support of our center and the CF Foundation.

Contributed by Dee Acquazzino

Travis Ferguson Memorial Fishing Tournament Results

1st Place: Shawn Holly & Bob Blecha-22.15 lbs.

2nd Place: Bryan Shaw & Joe Hopkins-19.8 lbs.

3rd Place: Bob Sargent & Roger Lisko-18 lbs.

The tournament raised a grand total of \$9,880 this year! Special thanks to Stevie Ferguson and Mark Lisko for organizing the event again this year.



Shawn Holly displays the winning fish, weighing in at 22.15 lbs.

Rock the Block Raises Record Funds

Rock the Block 2008, an annual outdoor event to raise money for Cystic Fibrosis research, was held in Cherokee, Iowa on the 16th of August. Cherokee is a moderate-sized rural community with lots of charm and character, located approximately one hour northeast of Sioux City. Rock the Block combines family fun with an end of summer musical celebration for the adults too.

The evening began with a pork producers' loin grill out, a classic car show and a kids carnival. Another large part of the event is the raffle extravaganza. A large building becomes home for the evening to a wide variety of prizes, including trips, tickets, certifi-



cates and all kinds of merchandise. More than 100 lucky people went home winners that night!

As the evening progresses, the music and beer garden begin to strike up a crowd and the party continues on into the wee hours of the morning. This year, Rock the Block hosted the "FishHeads" out of Council Bluffs as the headlining band.

Rock the Block 2008 raised over \$23,000, and broke previous attendance records. The event is sponsored completely by family, friends & local businesses, who share a motivation to find a cure for CF.

Contributed by Carrie Lux

Skin Care for CF

Are you getting everything you want from your skin care routine? Are you searching for a glamorous holiday look? Do you want stocking stuffers that also benefit CF? Through the end of the year, medical student and CF relative Katie Lessman is excited to conduct facials, skin care classes and holiday open houses and donate 33% of the proceeds to the CF Foundation. Use this opportunity to relax with friends and do some holiday shopping while your dollars count for double.

In addition, 25% of the proceeds from online sales will also be donated to the Foundation. Shipping is always free to anywhere in the United States. Simply mention "CF Foundation" when checking out at www.marykay.com/katie.lessman

To set up a skin care class or ask any questions, please contact Katie at katie.lessman@marykay.com or 402-301-6127.

Are you an artist?

Would you like to create a design that will be worn by thousands of people participating in GREAT STRIDES across the country? If so, then this opportunity might be for you...

The CF Foundation national office is looking for a new design for the 2009 *Team CF* T-shirt logo! If you have a flare for design and a passion for CF, this is a great opportunity—and a meaningful one: *Team CF* represents people coming together to fight CF.

Criteria:

- 3-color: One black and other two close to Pantone 301-U (blue) and 179-U (orange) or 200-U (red)
- Font must be Century 751 or Benton Sans
- Size should be full chest (not pocket or sleeve)
- Must say *Team CF* and Cystic Fibrosis Foundation
- Designed using Adobe Illustrator, or similar software resulting in a vector image



The deadline to turn in artwork is October 20th.

Please send artwork to Melissa Smigelsky: mismigelsky@cff.org.

2008 GREAT STRIDES
Team CF t-shirt logo

AN INSIDE LOOK: MAYOR FOR A DAY

One of the auction items at the Nebraska Golf Classic event was the opportunity for a child to spend the day with Omaha Mayor Mike Fahey. Brett and Julie Sesker purchased the item, providing a unique opportunity for their son, Jake. In the following letter, Jake reflects on his day as Mayor.

To Ms. Scheideler and Mayor Fahey,

Thank you very much for the awesome day that I got to spend with everyone. It was very interesting being involved in the pit bull meeting and very fun driving to Girls Inc. in the Mayor's car. The office was really neat and it was great seeing all the different jobs and pictures.

Thanks for donating the "Run the Town for a Day" Package to Boomer Esiason Foundation's Cystic Fibrosis Fundraiser. It was great that my parents could make a contribution to the foundation and that



Jake Sesker observes the view from the Mayor's podium.

I got to have an excellent experience from it. I learned a lot about what happens around the office. All the

meetings were interesting to sit in and see what the Mayor's normal day is. It was really cool to be at the check presentation because that night I went home and saw it all on television. All the awards Mayor Fahey had were fun to look at along with all the pictures of



Mayor Mike Fahey and Jake Sesker.

past Mayors. Thank you for lunch. Bob's was very good.

You have been an influential Mayor. Thank you for your service to our city. I appreciate your work even more after spending the day with you.

Sincerely,

Jake Sesker

Check out the link below for an article that appeared in the Newsweek magazine issue dated Sep. 12, 2005

“An Unexpected Reprieve: Thanks to new treatments, people with cystic fibrosis now have adulthoods they could never have imagined.”

<http://www.newsweek.com/id/104571>

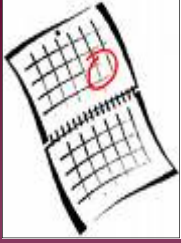
Extra ways to give \$\$\$

- 1) Search the Web *and* raise money for CF—for free! Search engine **GoodSearch.com** donates a penny back to charity for every search done from the site. Just go to www.GoodSearch.com and enter “Cystic Fibrosis Foundation” as your charity of choice and watch pennies turn into dollars for CF!
- 2) Planning on seeing a movie this weekend? Consider “**Proud American**”, a film about the American people. The CF Foundation is one of the beneficiaries of this film, which was written, produced and directed by Fred Ashman, a longtime friend and supporter of the CF Foundation. Check out the trailer at <http://www.proudamericanfilm.com/index.html>.
- 3) **Are you considering changing your cell phone service provider?** If you sign up for a new wireless plan through Verizon Wireless and the Qwest Direct Awards Program, the CF Foundation will receive \$15! Contact the Foundation at (402) 330-6164 if you are interested, and we will work together to secure those funds for the CF Foundation.
- 4) **Give a gift for a cure!** Gifts for a Cure provides an online giving opportunity where donations can be easily made to the CF Foundation in honor of someone or a special occasion. Donate now to send a beautiful e-card to your recipient. Or create a gift registry to celebrate your next special occasion. Visit <http://gifts.cff.org> to find out how your gifts can *add tomorrows every day* to the lives of those with CF!

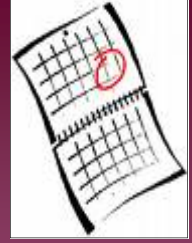


Update: Student Youth Board

We are looking for enthusiastic, outgoing high school students to take part in our *CureFinders* Student Youth Board! Board members attend a few meetings per school year, identify and recruit schools to participate in *CureFinders* and help facilitate the program at those schools. This is a great opportunity to gain leadership experience while making a difference in the lives of people affected by CF. To nominate a high school student for this unique opportunity, contact Melissa at the Foundation at (402) 330-6164.



Mark Your Calendars...



...with these important upcoming events and dates.

For more information on any of these events,
please contact the CFF office at (402)330-6164.

Columbus Great Strides

Saturday, October 11th

Pawnee Park

Columbus, NE

Come join the fun as friends and family take steps toward a cure!

Nebraska's Finest

Friday, November 7

Champions Run, Omaha, NE

Join us for our annual celebration honoring those who have made substantial contributions to CF research locally.

Enjoy food from P.F. Chang's, Kona Grill, Bob Monkey's Noodle Zoo, Julio's, Vivace, Flat Iron Grill, Great Harvest Bread Company, and Champion's Run.

This year's event honors Kayte Tranel, Abby Tranel, Pat Robshaw, and Jake Slosburg.

Individual tickets are \$50. Sponsorships range from \$1,000 to \$5,000.

THE NINTH ANNUAL RIMINGTON TROPHY PRESENTATION

Saturday, January 17th, 2009

Rococo Theatre, Lincoln, NE

Join us to honor college football's premier center at this black tie optional event.

The evening features dinner, an elite auction, and presentation of the award.

www.rimingtontrophy.com