

Helen & Ryan Frees continued

other races. "When I do these races, I like to think that I am running for Ryan," she said.

Helen has held several small school-based fundraisers for the NJSOCF and said she has told her students about the disease. "It's important for them to know that there are lots of differences among people, including physical ones," she said.

"I also emphasize this with Tegan, who lightens our day every day. She has been taught empathy and kindness. She knows how to relate to people of all different backgrounds and we are very proud of her. We have the support we need from family, friends, NJSOCF, and our doctors and we are very aware of just how precious good health is and work hard to keep it."



Helen, Tegan and Ryan Frees

NEW JERSEY STATE ORGANIZATION OF CYSTIC FIBROSIS

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First Fredericks Scholarships Awarded

NJSOCF is proud to announce that the Cheryl A. Fredericks Memorial Scholarship Fund has awarded its' first two scholarships. They will go to Erick Vilcacundo of Newark and Kelly Collins of Point Pleasant. Both scholarships are in the amount of \$2000.

The Cheryl A. Fredericks Memorial Scholarship Fund was established by her family to honor the memory of a wonderful young woman who never let CF stop her from living her life. Cheryl knew at a very young age that she would be an educator and a protector of the needy.

She attended college where she majored in psychology and special education. After graduating with honors she taught children with learning challenges. Always striving to do more to help children, she opened her own tutoring center in the evenings.

She was a very special individual and the scholarship committee is pleased to have made its awards to two students with similar values and determination.

Our Mission is...

To help ease the heavy financial burden placed on CF patients and their families and to provide needed information. No other cystic fibrosis organization in New Jersey provides the same type of focused financial assistance combined with education and counseling.

Our Motto: We are the ones who help them breathe easier!

How to Donate

In addition to contributing to our mail appeals, there are several ways you can donate to NJSOCF.

Memorial Gifts

A memorial gift to NJSOCF makes a lasting tribute to a departed loved one. Or a special occasion gift can be used to celebrate birthdays, anniversaries, and even given in place of wedding favors.

On-Line Giving

Making a donation on line is simple and convenient. Visit www.justgive.org and then type in "New Jersey State Organization of Cystic Fibrosis." Hit "open," click on "donate now," and you are set!

United Way

Employees that participate in the United Way payroll deduction program can designate their contributions 100% to NJSOCF. The United Way will happy to assist you.

Matching Gifts

Many medium-sized and large companies offer a matching gift program. Your employer will match your personal, tax-deductible donation to NJSOCF with an equal amount of company funds.

BREATHE EASY

New Jersey State Organization of Cystic Fibrosis

Established in 1977

"We are the ones who help them breathe easier"

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Helen & Ryan Frees

Ryan has not let having CF stop him from being a wonderful Dad and an attentive husband," said Helen Frees of Clark. "He doesn't let anything hold him back from participating in our family life. He is an incredibly thoughtful and appreciative individual, both to me and our five year-old daughter Tegan. Sometimes I get really stressed out but his love and support keeps me going."

Ryan and Helen were married in New Hampshire in 2007 after meeting through a friend. "We got engaged very quickly; we just knew" Helen said. "After marrying, we lived in Linden and a year later had Tegan through IVE. We call her our miracle baby because we were successful on the first try."

Helen said Ryan had been receiving help from NJSOCF for several years. "Basically since he was in high school," she said. "He told me about the assistance he received for prescription co-pays, nutritious foods, nutritional supplements and other items. His symptoms are both respiratory and digestive, and he suffers from chronic pancreatitis from time to time."

Ryan works in information technology, and Helen is a middle school art teacher in Westfield. Even though we are both working we really need and appreciate the help we get from NJSOCF," she said. "Without it our bills related to CF would be unmanageable."

Helen said that keeping Ryan's weight at an optimum level was very important and something she focused on. "We do our food shopping at Wegmans, using the adult program reimbursements, and it is a tremendous help to us. "I am able to get him a lot of foods we would not be able to afford and it is just a fact that healthier food is more expensive food. The nutritional supplements the program pays for are also very important."



Helen, Ryan and Tegan Frees

Helen said that in addition to the financial assistance the Frees family receives, they are blessed with a wonderful support system that includes the staff of NJSOCF and doctors at the Columbia-Presbyterian Medical Center in New York City.

"Dr. Emily DiMango is his doctor and she is just the best," Helen said. "The CF care team is happy that we are on the NJSOCF program and praise the help that it provides to us."

Emotionally, Ryan copes well with his disorder.

"He has the attitude that CF does not define him as a person," Helen said. "He is very active with his work, school activities and family events. When he does have a health setback, we figure it out together. I have learned a lot about CF and give him his physical therapy three to four times a week."

In addition to her teaching duties, Helen is an athlete who is planning on running in the New York Marathon this fall and has run in many

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Beefsteak Goes Over the Top

A large and lively crowd of NJSOCF friends and supporters packed the Brownstone in Paterson this past April 3 to feast on a delectable beefsteak dinner with all the trimmings, be entertained by well-known local comedian “Uncle Floyd” and take chances on loads of beautiful prizes and a 50/50 raffle.

Extra entertainment was provided by vocalist Greg Caldarone.

“This event was so much fun it was hard to leave,” said NJSOCF Executive Director Debra Sikkema. “There was something very special in the air that evening and everyone who came agreed it was one of our best fundraisers ever.”

Several supporters of NJSOCF really stepped up to the plate, making generous donations in amounts well over the \$50 price of admission.

“Special thanks are due to Mario Damiani of Dalma Dress Manufacturing; the Calabrian National Forum, Inc.; and Mark Donnelly of Mark Donnelly & Son Construction who added to the night’s receipts,” said Ms. Sikkema.

Supporters were very generous with their purchase of raffle tickets for 30 different items that included “big ticket” items like a Sharp 32” LED TV; an All-In-One Color Ink Jet Printer; and an overnight stay with breakfast in a luxury one-bedroom suite in the Grand Cascades Lodge in Hamburg.



George McDermott, CF Adult Spokesman and Uncle Floyd

The always hilarious Uncle Floyd kept the evening lively, with laughter filling the room as he went through his familiar and well-loved routine of jokes.

“This is a fundraiser we won’t soon forget,” said Ms. Sikkema. “NJSOCF thanks everyone who turned out at the Brownstone and we will definitely be doing it again next spring!”

Casino Night a Big Hit

Rich and Kaitlyn Boisch wanted to do something special to thank our organization for helping Kaitlyn cope with CF. The lovely 28 year-old woman has been on our adult program for the past several years and both she and her husband are deeply appreciative of the help they have received.

“I hit upon the idea of reviving a Casino Night fundraiser our New Brunswick Rotary Club had done a couple of years ago and putting some new life back into it for NJSOCF,” said Rich. “The local Elks Club donated their space, which had a bar and kitchen, for us to use the evening of February 8. The event was a big success, raising more than \$7,000 for the programs of the New Jersey State Organization of Cystic Fibrosis. We were all thrilled with the great result.”

Rich met Kaitlyn ten years ago when he was working in her father’s hardware store in Somerset. “We began dating and she told me about her CF,” he said. “As we continued to get to know one another I saw how much effort it took for her to maintain a healthy lifestyle.”

Rich said Kaitlyn copes with CF very well, even though she does have some down times. “But usually she feels positive and well,” he said. “She had been working part-time until recently but we decided it was too much and she is now about to start receiving disability after her fourth hospitalization.”

Rich said he believes the Casino Night was so successful because of its highly defined cause. “It was all about raising funds for cystic fibrosis,” he said. “Close to 100 people came and everyone was very generous. We got sponsorships from people that couldn’t attend and the people that came really opened their wallets. Winning chips were exchanged for prizes at the end of the evening, and Rich said there were plenty, including lots of restaurant dinners; theater tickets; sports tickets, a 32” TV and much more.

“Everyone had a great time and we are looking forward to doing it again next year,” he said. “On behalf of both Kaitlyn and myself I want to thank NJ-

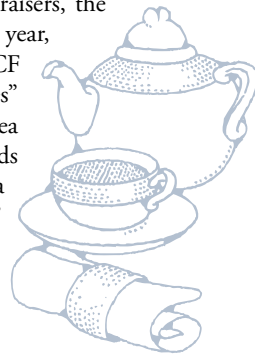
SOCF for all you have done. When finances were tight for the things Kaitlyn needed, you really came through. We are very happy to have raised this money to help your organization.”



Special Events – Coming and Going

Mother’s Day Tea

Always one of our most successful fundraisers, the Mother’s Day Tea did not disappoint this year, raising over \$13,000 to support NJSOCF programs. Each year our loyal “hostesses” send out pretty invitations including tea bags provided by Wegmans to their friends and relatives, asking them to join in a “Make Believe” Mother’s Day Tea Party” where they stay home brew a cup of tea, and then make a donation of their choice to NJSOCF.



Fall Raffle Dinner

This year will mark the 38th edition of the NJSOCF Fall Raffle Dinner. The event is set for Thursday, Nov. 7 at the Westmount Country Club in Woodland Park. As always, NJSOCF organizers are working hard to collect hundreds of fabulous prizes that will be raffled off at the event. Entertainment and a Silent Auction, featuring an array of fine items will complete the festive evening.



Tickets, which include a delectable three-course dinner, are \$60 or supporters can sell six raffle books and come for free.

Annual Golf Tournament

The NJSOCF 31st Annual Golf Tournament is scheduled for Friday, Aug. 1. Entering its third decade this year the always popular and fun filled event will once again be held at two beautiful courses: the Ballyowen Golf Club and the Wild Turkey Golf Club, both in Hamburg.

Awards and golfing prizes will be given out at the traditional post-tournament awards dinner at the luxurious Crystal Springs Country Club, also in Hamburg.

Invitations with full information will be mailed shortly. For information call (973) 595-1232.

Bowl for CF Awareness Set for November

The annual “Bowl for Cystic Fibrosis Awareness” fundraiser is set for November at the New North Arlington Bowl-O-Drome in North Arlington.

Bowl for Cystic Fibrosis has a two-fold-purpose. It will help raise the level of public awareness about the life-shortening disease and use funds raised to support programs offered by NJSOCF.

George McDermott of North Arlington will once again serve as event coordinator. Mr. McDermott is a CF patient, and is a dispatcher for the North Arlington Police Department and an EMT, who has battled the disease his entire life and never let it defeat him.

Out of the Mailbox ...



Dear Debbie –

It has been really busy. Tommy is graduating this year as you know. Yesterday he got out of CHOP for a tune up and hopefully he will feel better soon. On Tuesday night he sent me a text that he has never felt this bad before. The reality of his disease has reared its ugly head. I am upset and just want him to be able to go away to college and have a great time and enjoy his life.

I am sure this, too, will pass. Tommy has a great outlook and attitude along with great friends.

Thanks for your continued support and reimbursement for the meds and groceries. It really helps a lot. I appreciate

all you are doing for the CF community. You probably don’t hear that enough.

Haddonfield, New Jersey

Dear Debra –

Many thanks to you and those who donate to this worthy cause. Reimbursement was recently received for IV and prescription out of pocket expenses. This was deeply appreciated. Your financial assistance is the difference between “sink or swim” and helps alleviate some of the stress due to this difficult disease.

Thanks you so much for your compassion and assistance.

Hopatcong, New Jersey

Dear Debra –

Thank you so much for doing the food reimbursement. As a college student who enjoys food and misses home cooked meals it is great to know that I can still afford to eat healthy away from home.

Just wanted to let you know it is appreciated tons.

Egg Harbor Township, New Jersey