

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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ERICA CENCI – Living Her Dream

From the time she was a little girl in Westfield, Erica Cenci loved to sing and dance. Even though she had been diagnosed with CF at birth, it didn't slow her down. And it hasn't to this day. Erica, now 29, is forging a career in musical theater, singing and dancing her way across America in a variety of productions that have included such Broadway stalwarts as *Cats*, *Fiddler on the Roof* and *A Chorus Line*.

Erica has received assistance from NJSOCF since joining our adult program in 2006.

"My parents, Linda and Victor, told me there was nothing that I could not do," she said. "Even though they had never dealt with cystic fibrosis and had a huge learning curve with me I was allowed to follow my interests, which by the age of three, included putting on musical shows in front of our fireplace mantle."

The Cencis enrolled Erica in the nearby Lois Allen School of Dance in Clark, New Jersey and she has kept up with singing and dancing ever since, fulfilling her childhood dream.

"I was fortunate to not have any severe symptoms and had a great time at Westfield Senior High School," she said. "I loved my teachers and had lots of good friends. I ran cross country and was involved in drama and dance programs. I was probably in the best shape of my life."

Erica suffered only a few minor glitches with CF in high school. "I was put on an IV for the first time in my life at the same time I was to appear in our school musical, *Godspell*. I was freaking out because I didn't want to drop out and my teachers changed my costumes and choreography so I could do the show with the IV in my arm. I wanted to prove I could do it, and I did."

Erica said all of her friends have been very supportive as she has moved on through her life. "I have never been treated as though I was different and my parents have always been amazingly supportive."

Muhlenberg College in Allentown, Pennsylvania was the next step in Erica's musical theater development. "I majored in theater, with a concentration on performing, and in English," she said. "By that time I was pretty sure I wanted to perform in musical theater as a career. Muhlenberg has a good balance between the performing arts and liberal arts. At the same time I was taking private voice lessons, and dance classes."



Erica, far right, performing in a production of "A Chorus Line"

Touring "Off Broadway"

Erica got her degree in 2006 and set out to pursue her dream of musical theatre. "I was still living at home and commuted to New York City for auditions and landed a role with the American Family Theatre, headquartered in Philadelphia, to tour for three months in *A Christmas Carol*. This was a new experience, being on the road with all of my medications and equipment. We toured the middle of the country, with seven of us in a van, driving through heavy snows. I went, survived, came home and kept on auditioning."

The following year, Erica toured with another children's show and then appeared at the Williamstown Theater Festival in Massachusetts. From there, she was cast in more summer theater.

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Golf Tournament – Going Strong After 30 Years

Friday, August 2 proved to be a perfect golfing day and a large crowd of faithful supporters turned out for our 30th Annual Golf Tournament. Marking its third decade this year, the always popular and fun filled event was held once again at two beautiful courses: The Ballyowen Golf Club and the Wild Turkey Golf Club, both in Hamburg.

Awards and prizes were presented at the traditional post-tournament awards party at the luxurious Crystal Springs Country Club, also in Hamburg.

“It’s hard to believe this year marked the 30th anniversary of our golf tournament,” said NJSOCF Executive Director Debra Sikkema.



Board member, Deb DuHaime, at Ballyowen Golf Course

“It’s been three decades of fun and raising money for our very important cause. The golf tournament is our biggest fundraiser of the year and we count on the money we raise to help run our programs. Fortunately, this year was a very good one, and I would like to thank our dedicated committee, and everyone who turned out to support NJSOCF and the patients we serve.”



Board member, Philip Luppino, far left, with friends



Board member, Joe Müick, far left, and his foursome

Adult Program Update

Our state funded program for cystic fibrosis adults age 18 and up has served hundreds of patients from every corner of New Jersey since the program started in 1990. This year we have our largest caseload ever.

Services available include financial assistance for:

- Prescription drugs and co-payments
- Medical equipment and supplies
- Nutritional supplements
- Extra nutritious foods

All are provided according to mandated limits established by the program.

Other services provided include:

- Coverage for health insurance deductible
- Public and patients education
- Emotional support
- Referrals

The overall objective of the adult program is to enable CF patients throughout New Jersey to continue to live their lives as happy, healthy and productive members of their communities.

To enroll, call the adult program administrator at (973) 595-1003 for an application or download one at www.njsocf.org.

Thanks to NJSOCF

Dear Debra :

The Frees family of Ryan, Helen and Tegan would like to thank NJSOCF for the immense help they give to our family. Ryan is on many expensive medications that have fortunately given us a good year so far, and the help we get paying co-pays is invaluable. For others with CF, the Tobi Podbaler has been really successful and easy for Ryan. The nutritious food program is the best! We shop at Wegmans and are able to buy nutritious food that we have figured out lasts us the entire month! We cannot tell you how much we value the help you give us. We work hard and only have our one little Tegan, but there is never enough ways to say that the help paying for food and prescriptions has changed our lives.

Everyone who works at the NJSOCF is kind and truly cares for our family. You are a part of our family and we cherish your help! Thank you!

Helen, Ryan and Tegan Frees

Paradise Family Hosts “A Night of Hope”

The Paradise Family of Marlton know how to give a good party, and give one they did this past Sept. 13 to benefit the New Jersey State Organization of Cystic Fibrosis.

Called “A Night of Hope” the fully sold-out event was held at the Indian Springs Country Club in Marlton.

“We put on the party to support the New Jersey State Organization of Cystic Fibrosis, which has been wonderful to our 23-year old daughter Devon and our entire family,” said Devon’s Mom Betsy, chief organizer of the event. “A Night of Hope,” featured a sit-down dinner, dancing, an auction and scores of raffle items. About 245 supporters were in attendance and Ms. Paradise said everyone had a great time and went home happy.



Devon Paradise, second from right, with friends at “A Night of Hope”

The family decided to dedicate the event to the NJSOCF because Ms. Paradise said “They are so very helpful to us and have been lending us emotional and financial support for the past five years, when Devon was old enough to enroll in NJSOCF’s adult program.

Ms. Paradise said NJSOCF has been of tremendous help to her family, especially with nutritional supplements and over the counter medications.

“Devon’s story”

Devon was diagnosed with CF at five months of age after having one lung infection after another and failing to thrive. “We had a sweat test and the diagnosis was made,” Ms. Paradise said. “We were always very aggressive with her treatments and kept on top of things.”

Ms. Paradise said Devon was healthy as a young child but once she reached high school her symptoms became more severe. But she was a fighter, kept up with her school work and treatments and completed college in three years.

“She is a remarkable young woman,” her proud mother says. “She now works full time for ARI, a division of Holman, a regional car dealership.”

Ms. Paradise says Devon goes to work every day with a positive, upbeat attitude. “I always told her that she was unique and that she should share her story with her friends, which she does. She doesn’t shy away from things.”

Ms. Paradise said NJSOCF is “a place where you always know you can call and get help. They are so obliging and truly there for all the right reasons. They get it. They know what living with CF entails and the support the staff supplies is a Godsend. There have been many times when I have cried on the phone, talking about Devon, and they have shared my tears and given me comfort. They are simply the best.”

2014 Special Events

February

Beefsteak Comedy Night, featuring top comedians from television and movies!

Spring

12th Annual Sunset Bowl
T Bowl II, Wayne, NJ

March thru May

Mother’s Day “Make Believe” Tea Party
Please join us as a hostess!

June

Look for our Spring Newsletter and Membership Drive.

August

31st Annual Golf Tournament
Ballyowen Golf Club and Wild Turkey Golf Club, Hamburg, N.J.

November

37th Annual Fall Dinner
Bowl for CF Awareness, New North Arlington Bowl, North Arlington, N.J.

Look for our Fall Newsletter and End of the Year Appeal.

Volunteers are urgently needed to help us run these fundraising events and make them a success. Whether it’s getting out mailings, soliciting prize donations, or helping out the day of the event, there is plenty do and extra help is always needed. Call Debra Sikkema at (973) 595-1232 to talk about lending a hand.

Cheryl A. Fredericks Memorial Scholarship Fund

NJSOCF is happy to announce that applications will be available in January 2014 for CF patients, family members, or siblings who reside in the State of New Jersey. Two \$2,000 scholarships will be awarded for the 2014-2015 academic year.

For more information visit our website in January or email Debra Sikkema at das@njsocf.org.

Erica Cenci – Living Her Dream continued

“I did 42nd Street in summer stock in upstate New York and Fiddler on the Roof in regional summer theater in Pittsfield, Massachusetts.



Erica Cenci

By this point Erica had moved in with friends in New York City to make auditioning easier and got booked into two national tours. “I did Cats in 2008-2009 and then A Chorus Line in 2010 and 2011,” she said.

This period of her life was quite demanding. “I did eight months at a clip with only a couple of breaks. I was traveling with all of my medications and equipment but thankfully everyone was very supportive.”

Erica changed directions somewhat at the Paper Mill

Playhouse in New Jersey where she was assistant director and choreographer for their production of The Sound of Music. “Being on the other side of performing was a huge and valuable learning experience,” she said.

A Setback

Erica did another tour of A Chorus Line in Texas earlier this year and was all set to complete rehearsals for Cats when she tore her ACL knee ligament. “I had surgery several weeks ago and am recovering well, doing physical therapy and hope to be back to normal in about six months.”

In the meantime, Erica has another focus that keeps her busy – preparing for her marriage to Bryan Cordes in June of 2014. “He is a social worker, not an actor, which is wonderful,” she said. “The wedding is shaping up to be a big affair so I have plenty to do while I recover.”

Erica said she is happy with the course of her life. “It’s a lot about how you are thinking every single day,” she said. “It’s up to me to properly manage my day to day care. Sometimes it’s hard because of work, auditions, or whatever. But I know I have to do it. My parents still support my desire to be a performer. It’s a lot about your family. They gave me a positive attitude that has stayed with me through life and I wouldn’t be the person I am without them.”

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.

Longtime staff member Rosemary Schroeder passed away suddenly this past June.

Rosemary was a valued employee who deeply loved NJSOCF and was with us since our founding.

She is greatly missed by everyone whose life she touched.



Rosemary Schroeder
March 7, 1957 – June 10, 2013

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