



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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Tania George: The call that changed her life!



The call came on November 29, 2017, and on November 30th Tania received her new lungs and her life was changed forever.

Tania George, now 37, was diagnosed at age three with cystic fibrosis and led a mostly normal childhood doing vest and nebulizer treatments daily. Not until she was 17 did she need IV antibiotics every four years.

"In 2006 I married a great man and two years later we bought a house next to my parents," Tania said. Eventually her sister was married and moved in across the street. "I feel I'm blessed that I grew up in a family that was very close and supportive," she said.

Soon after in 2012 Tania started her family and gave birth to beautiful twin girls, Gianna and Kylah, now six and a half years old.

Then four years later her life was turned upside down. Tania was hospitalized for chest infections every three months, then two months, then every month. "I felt like I was living in the hospital," she said.

By December 2016 she was told by her doctor that her future was headed towards a lung transplant. "I waited until after Christmas to tell my family that I needed a double lung

transplant," she said. "By being in the hospital every 2-3 weeks the nurses became my friends."

By 2017 Tania was on oxygen 24/7. She started her evaluation tests for transplant at Columbia Presbyterian and four months later she was on the transplant list for Columbia. In July of that year she was also double listed at Beth Israel in Newark to improve her chances of getting new lungs.

As her health deteriorated her mother was her caretaker while her husband was at work. "Without my mom and sister helping me throughout this time, I don't know how I would have done it." Tania said.

And then the call came.....and she received her new lungs the next day.

Continued.....

Special Events coming and going.....

“POCKETBOOK BINGO” April 12, 2018

On April 12, 2018 friends and supporters of NJSOCF once again filled the Pompton Lakes Elks Lodge to play Bingo for Designer Handbags and raise awareness for cystic fibrosis. “No one seems to tire of this event. We sell out every time,” said Executive Director, Debra Sikkema. “It’s so much fun to play bingo and who wouldn’t want to win a gorgeous handbag!”



35TH ANNUAL GOLF TOURNAMENT August 4, 2018



NJSOCF hosted our 35th Annual Golf Tournament this past August.

With old friends, a beautiful course and scenic views—Crystal Springs never disappoints. This wonderful tradition and NJSOCF’s most important fundraising event raised much needed funds for the CF Community in New Jersey who benefit from our assistance programs.

Bowl for CF Awareness

The annual Bowl for CF Awareness fundraiser was held on Saturday, November 10th at the New North Arlington Bowl, Schuyler Avenue, North Arlington. NJSOCF board member, George McDermott, once again did an outstanding job raising funds, and more importantly, raising awareness for Cystic Fibrosis. Many of North Arlington’s finest turn out for this event, and everyone always has a great time.

Coming in 2019.....

Pocketbook Bingo—Spring

“Make Believe” Mother’s Day Tea Party—May

36th Annual Golf Tournament—Summer

Bowl for CF Awareness—November

Visit our website for additional events and more information www.njsocf.org

Alan Barone scores a touchdown at Garmany Boom!

NJSOCF President, Alan Barone, recently attended “Garmany Boom!” a fundraiser for the Esiason Foundation sponsored by the Garmany store in Red Bank. Alan is seen here with Boomer Esiason whom he met and spoke with about the New Jersey State Organization of Cystic Fibrosis. Executive Director, Debra Sikkema said, “I’ve since been in touch with the Esiason Foundation staff with regard to what we do on behalf of the CF community in New Jersey. We also spoke about future cooperative endeavors with the Esiason Foundation.” NJSOCF wants to thank Alan for attending the event and informing Boomer personally of our mission and letting him know we are here as a resource for individuals with CF in New Jersey and their families.



Kalydeco & Symdeco...the tip of the iceberg!!

By Dave Berkenbush

As with most medical drug research in today’s diseases and ailments, modern day 21st century technology has literally transformed the field of medicine.

None are more transformed than the field of CF drug research. Before the turn of the current century, most drug research was primarily focused on the symptoms of the effects of CF on the lungs and pulmonary systems. Much of the success was in the area of antibiotics—both oral and inhaled. These antibiotics did and still do much today in abating the damaging effects of CF on these systems.

The oral drugs—initially expensive for the consumer—began to drop dramatically. The inhaled drugs, i.e., Tobramycin, Cayston, Colistin and Pulmozyme today remain quite expensive though affordable through the assistance of pharmaceutical grants and grants such as NJSOCF Pharmaceutical Services for Adults with Cystic Fibrosis. These grants have become essential in the continued viability of CF treatment therapies in New Jersey.

However, a revolutionary trend took place in the early part of this century. The field of technology in the area of genetic drug research had literally transformed CF treatment therapies, no longer just addressing the symptoms of CF, but now the underlying causes of CF.

Studies began in addressing many different aspects of the genetic and biological causes of CF on those affected and new genetically modified drugs began to be approved by the FDA.

As a result of these research efforts within the last few years, drugs like Kalydeco, Orkambi and Symdeco are now available to most CF patients, with many more genetic modifiers on the horizon. But not without financial consequences, straining the viability of grants such as NJSOCF to continue to assist the CF community.

For those CF patients with private insurance, in most cases coverage can be obtained with the help of pharmaceutical grants like GPS through Vertex Pharmaceutical. However, those who are no longer working, because of the progressive nature of CF and who are on Social Security Disability through Medicare, do not qualify for the Vertex grants. Otherwise, organizations such as NJSOCF are attempting to fill in this co-pay gap, which is becoming a marked financial burden.

The average monthly cost of these newly released drugs can be compared to the purchase of a new vehicle due to the R&D factor that the pharmaceutical companies pass on to the consumer. Hopefully, in the near future, healthcare reform can address and remedy these out of control drug costs and relieve some of the financial burden placed on individuals with CF and their families.

Tania George continued from page one.....



Tania is one year post transplant now and loving her life. Aside from some minor side effects, such as weight gain and hand tremors, she doesn't do any more treatments, including vest, inhalers, nebulizers or chest P.T. She has more time for herself and her family, being a mom to her kids and a wife to her husband. Now she joins her family for walks in the park.

"Every day when I breathe deeply I thank God how lucky I am. I also thank my donor's family for their selfless decision and this beautiful gift of life I have." Tania says.

"It was like just yesterday I felt like I was drowning; I could barely breathe. Today I'm breathing like a normal person. Every day when I wake up I ask myself—is this for real?"

Our Mission is...

To help ease the heavy financial burden placed on individuals with CF and their families and to provide needed information. No other cystic fibrosis organization in New Jersey offers the same type of focused financial assistance and emotional support.

Our Motto is...

We help them breathe easier!

New Jersey State Organization of Cystic Fibrosis

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How to Donate

On-Line Making a donation on line is simple and convenient. Just visit our website—njsocf.org.

Memorial Gifts

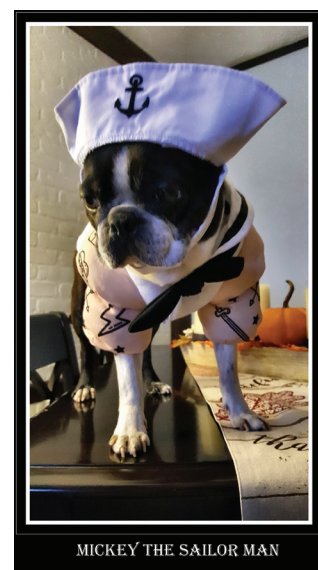
A memorial gift to NJSOCF makes a lasting tribute to a departed loved one. A special occasion gift can be used to celebrate birthdays, anniversaries, and even be given in lieu of wedding favors.

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.

United Way

Employees that participate in the United Way payroll deduction program at work can designate their contributions 100% to NJSOCF.



MICKEY THE SAILOR MAN

Office Mascot Mickey dresses for Halloween!