



# BREATHE EASY

New Jersey State Organization of Cystic Fibrosis

Established in 1977

*"We are the ones who help them breathe easier"*



Volume 31

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## Our Mission

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 offers the same type of focused financial assistance and emotional support.

## Our Motto

We help them breathe easier!

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## "Little One"

### A Poet's Voice Resounds Through Decades

By Mary Jo Malanga

Although his time with us was all too brief, Robert Malanga's longevity for a patient born with CF in 1953 was a remarkable blessing. He managed to have a happy, somewhat normal and somewhat extraordinary life, co-existing with the forever stalking illness. As it taunted his physical health and at times kept him out of the mainstream of social life he so enjoyed, he took none of the simple joys of life for granted. He developed profound pensiveness, imagination, a clever sense of humor and his positive view of life which are reflected in the artwork, cartoons and poems he left behind for us.



heart and became a professional cartoonist for newspapers in New Jersey and national magazines. All the while he co-existed with the CF Stalker, pushing it out of his way, although sometimes it pushed back hard. Robert remained determined to laugh often, have fun and live life to the fullest.

The poem "Little One" was written in 1993 for our daughter,

Nina, when she was five years old. Like many young children, Nina was having nightmares and was afraid to go to bed. The poem is a reminder of the wonderful things that happen when you close your eyes to go to sleep, the places you go, and the friends you meet in dreamland. For many years I'd give a copy of this poem to children at

showers, births, and birthdays. It holds a special wish for all children.

Almost 30 years later, Nina surprised me with her plan to publish "Little One" as a children's book. She found the right artist amongst her many friends, Erin



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Schuetz, who created superb illustrations that brought the book visually to life. Erin used Nina's favorite stuffed animals from childhood to create "The Dream Team" that accompanies the Little One on her nocturnal journey, replacing fear with fun.



Nina launched a Kickstarter to fund the publishing of the book—the Kickstarter goal was fulfilled in an amazing few days, and was highlighted by the Kickstarter platform as "As Project We Love." Six hundred copies of the book were printed, most of them taken on pre-

orders to the family and friends who always treasured Robert's work and were overjoyed to share an actual book with their own little ones. The remaining are available on Amazon (search Little One Robert Malanga/Erin Schuetz) and a second publication is anticipated.

Reflecting now while writing this article with the book on my desk, I'm thinking how Robert discovered he just couldn't push the CF Stalker out of his way, as he gallantly

hoped he could. He needed his CF Dream Team, including family, friends, the many doctors and medical professionals, the VNA, the pharmacists, the CF Foundation, which focuses on funding research for the cure, and the NJSOCF which provides comfort in community and greatly needed financial relief from medical costs. Robert learned that the CF Stalker couldn't just be pushed aside, but it could be tamed and managed with his devoted Dream Team. This year marks 20 years since Robert passed. The CF Dream Team keeps going and because of this, the quality of life for CF patients is greatly improved and hopes and dreams abound.



Nina published and dedicated this book "For all the Little Ones." Of course, this means all the little ones coming along as life marches on. It also includes everyone, all of you, because what is embodied in this lovely book is timeless wisdom and inspiration to live life with courage and a spirited sense of adventure and fun.

### **Office Chit Chat...**



*Debra in the middle with her brother and his family*

Another major milestone has been reached this past year for NJSOCF. Twenty years ago Debra Sikkema took over the helm as Executive Director of NJSOCF from her mother and founder, Estelle Sikkema. Debra has been at her mother's side since childhood when she was modeling in fashion shows at 3 years old with mom, when Estelle was a Trustee for the newly formed "National Cystic Fibrosis Research Foundation" (eventually renamed the CFFoundation). She was alongside her mom in 1965 when Estelle became the first Executive Director in New Jersey for the Foundation, and Debra was witness to the new organization, NJSOCF, her mom founded in 1977 to provide hands-on financial assistance to the CF community in New Jersey.

During her over two decades tenure as Executive Director of NJSOCF, Debra has been able to transform the organization as one of the leading assistance and resource groups in New Jersey, dedicated to the CF community.

In addition to community outreach thru health fairs, enhanced website interaction with the CF community, NJSOCF also sponsors fundraising events such as the Annual Golf Tournament, bi-annual Pocketbook Bingos, "Make Believe" Mother's Day Tea Party, and Newsletters, which assures the success of the organization.

"I am honored to continue the work that was my mother's vision, and honored to continue to help the CF community in New Jersey," said Debra.





## Tania George: Five Years Strong

Where do I begin...well for starters I'm still here and alive! My name is Tania George and I'm 41 years old. I've been married to my wonderful husband, Karim, for 16 years, and we have 10 year old twin daughters. As some of you may know, I contributed to the CF newsletter back in 2018 highlighting my journey leading up to a double lung transplant and the recovery period after. November 30, 2017, a day I will never forget, I received a phone call that would forever change my life. Fast forward five strong years, post-transplant, and I am enjoying life more than ever!

Even if you don't have CF I'm sure you can imagine that the transplant world is not a walk in the park. I once read that having a double lung transplant is not a cure for cystic fibrosis, only a bandage. After my transplant, I encountered many hurdles and bumps along the way. When COVID-19 entered our world, the lockdowns were difficult for everyone, and I was diagnosed with COVID-19 right after my daughter's ninth birthday



in March, 2021. Because I am immunosuppressed I was admitted to the hospital for a day, and heavily monitored while given antibodies. I consider myself very lucky that things didn't take a turn for the worse and this hurdle was overcome.

Now that COVID restrictions have lifted, everything is open and masks are now optional in most places, I'm enjoying life and not afraid anymore. Of course I'm still very careful and cautious, and I keep my guard up, but I am living my life to its fullest.

We added a new family member, Buddy, a dog we adopted this past April. Buddy fills our hearts with so much joy and excitement. My family and I went on our first camping trip with Buddy this past summer and had the time of our lives. I am forever grateful to God and for my donor who gave me another chance at life. I am now creating new memories with my family that I will cherish each day of my life.

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## Pocketbook Bingo Spring 2022

After a long hiatus due to COVID-19 we resumed our famous Pocketbook Bingo!

On March 31, 2022 friends and supporters of NJSOCF once again filled the Pompton Lakes Elks Lodge to play Bingo for twelve fabulous designer handbags and raise awareness for Cystic Fibrosis. Supporters also enjoyed an upscale Tricky Tray, refreshments and 50/50 Raffle. "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!"

***Thank you to everyone who attends and for all our devoted volunteers who make this event a rousing success!!***





# 39<sup>th</sup> Annual Cystic Fibrosis Golf Tournament

## at Wild Turkey Golf Club



Friday, August 5, brought together old friends and supporters of the Annual Cystic Fibrosis Golf Tournament at Crystal Springs in Hamburg, New Jersey.

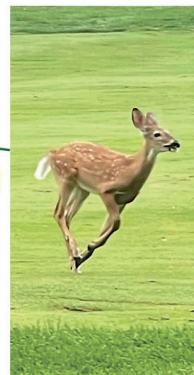
This year marked our 39th Annual Golf Tournament and Mother Nature gave us another beautiful day with just enough light rain to cool us off. Participants enjoyed

a BBQ lunch, a round of golf at Wild Turkey Golf Course, cocktail hour and awards dinner under a huge tent at the beautiful Crystal Springs resort.

We take this opportunity to thank our hard working committee, our loyal supporters, devoted volunteers and our special sponsors, Mr. and Mrs. John Lee; Philip Luppino and V.A.L. Floors; Mike Weinberg and Ernst &



Young; John Pierkarski and Ally Construction Services; RAM Medical, Inc.; SBF Construction, Inc.; Levine Builders; Mike DuHaime and Mercury; Sweeney & Harkin; RMG, CPA, LLC; and all the other donors and golfers who contributed to a successful event. Thank You!



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Office Mascot Sunny enjoys home and hearth.

## HOW TO DONATE

**ON-LINE:** Making a donation on line is simple and convenient. Just visit our website—[njsocf.org](http://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.

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