



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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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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Celebrating 48 years of helping the CF Community!

Nobody in New Jersey does it better!



Forty-eight years ago NJSOCF was founded by Estelle Sikkema and a small group of dedicated people for the sole purpose of alleviating the financial and emotional burdens placed on CF families in the State of New Jersey. Although the organization started small, our dreams were big, and through our programs of direct patient aid, Estelle would be proud to know that NJSOCF does make a difference in the lives of those who courageously meet the challenges of living with cystic fibrosis.

"Thanks again for all you do. We don't know what we'd do without your help!"

A genetic disease, CF affects the lungs and pancreas. It causes normal lung secretions to become thick, resulting in strains on the respiratory system, causing life threatening lung infections. In the pancreas, it affects the metabolization of

nutrients. Both parents must be carriers of the defective gene in order to have a child with cystic fibrosis.

"We are so grateful for NJSOCF's help over the last few years. You have certainly helped to ease what you well know to be a heavy burden."

In addition to our special Adult Program, NJSOCF provides services to patients from infancy onward. Aside from a state grant which funds a portion of Pharmaceutical Services for Adults with Cystic Fibrosis, all of our other efforts have depended on fundraising and donor contributions.

NJSOCF Adult Assistance Program

Thanks to major advances in diagnosis and treatment of the disorder, average life expectancy for CF patients is on the rise. And not only are CF patients living longer, they are living better, forging careers and having families.

"You guys rock and I seriously don't know what I'd do without the help from you."

But along with a longer life comes increased financial needs, many CF patients have inadequate medical insurance and problems financing the daily costs of living with the disorder.

"Your financial assistance is the difference between "sink and swim" and helps alleviate some of the stress due to this difficult disease."

Estelle recognized this change in the needs of CF patients living independently

Continued...



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and financially on their own and decided to find ways of funding a special program for adults, now known simply as "NJSOCF Adult Assistance Program."

"I very much appreciate your support. It is tremendously helpful to know there are people on our side as we navigate the various challenges of cystic fibrosis."

The adult program provides financial assistance to eligible New Jersey residents age 18 and over for the purchase of prescription drugs, medical equipment and supplies, oxygen, home IV's, vitamins, nutritional supplements and nutritious foods, reimbursement of co-pays for doctors' visits, lab/diagnostic tests and mental health visits, all necessary for the treatment of cystic fibrosis. The program also provides up to \$1,000 per year towards insurance deductibles.

Counseling is essential

Individuals with cystic fibrosis are not encouraged to be around others with the disease for fear of cross-infection. For some clients, especially those without family or

support systems, it can be a lonely life. Our clients feel free to call or come to our office just to talk about their lives and the day-to-day issues they face. Problems unique to people with cystic fibrosis are talked about frankly and openly with our staff.

"Most of all thank you for the help you provide us with supplements. I really appreciate it (even though I forget to write back). Thank you again!"

We work closely with social workers at CF centers and their clients directing them toward prescription drug programs, contracting and scheduling home IV services, purchasing or renting equipment, purchasing appropriate food and supplements, and generally assisting them with any other issues that may arise.

"Thank you so much for the blessing that the organization provides. My family and I are so grateful!"

Our overarching mission is to help ease the heavy financial burdens placed on CF patients and their families and to provide much needed information and compassionate support.

We are proud to say "Nobody does it better!"

A Thank You Note from Dave Berkenbush



I want to express my gratitude to NJSOCF's for their help and assistance while I lived most of my life in New Jersey. I was one of the first adult recipients of Pharmaceutical Services for Adults with Cystic Fibrosis back in 1990. In fact my client number was No. 1! Now I believe the numbers are well into the five hundreds. Back then, Executive Director Debra Sikkema's mom, Estelle, was the director. She was always a great supporter of me and an inspiration as well. During those years and going forward until I moved to Delaware last year, NJSOCF was

always there for me through tough financial times.

During my youth and before diagnosis, I had always been sick and out of school numerous days. While in college, I also experienced sick bouts, never having realized nor understood why I had so many digestive and respiratory problems. Once I was even asked to leave a class for coughing. Although I had two brothers with CF I wasn't tested until after college.

Finally, after college at age 23, I was diagnosed with cystic fibrosis. Those were the beginning years of working towards my career. Even though I had been diagnosed with CF, I was still able to work, although my medical problems led me from job to job. But in between those jobs NJSOCF was always there to lend me a helping hand. As a token of my esteem, I also worked very closely with NJSOCF through the years as a willing and dedicated volunteer. My friendship

with Deb and Bernice grew during those times. In fact, I was referred to as Number 1 Volunteer! All the way back to the early 90's I participated in the fall luncheons, the fashion show dinners, "Pocketbook Bingos," Golf Tournaments and even mailings and helping around the office. I always felt like I was a part of a close family, and still do! Last year I moved to Delaware, but I still think about my years with NJSOCF, and am grateful for the many great memories that I still have. Thanks NJSOCF for being such a big part of my life!





Thank you Alan!



Alan Barone has been at the helm of NJSOCF since 2002 as President of our Board of Directors. Last year Alan passed the torch to George McDermott but remains on the Board as Vice President. Alan has supported NJSOCF throughout those years never missing a golf tournament, or a Fall Dinner, a Beefsteak, Casino Night, and most any other event to raise funds and

awareness for NJSOCF. Typically he would emcee the events and became a familiar face of the organization. He first became involved with NJSOCF years before becoming President through Anne and Tony LoSasso who were active volunteers for the organization, and had two daughters with CF. He saw first-hand what a devastating disease it could be.

Before Alan became a financial advisor he was able to help the organization through his previous business using delivery trucks to deliver materials to different NJSOCF special events. He gradually became more and more involved with the organization. Finally, Estelle Sikkema, the Executive Director at the time, made Alan an offer he couldn't refuse and

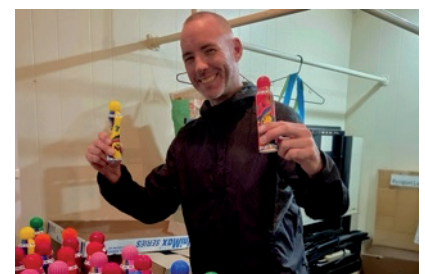
asked him to take the position of President. Not many people could say "no" to Estelle and the rest is history.

Alan, we cannot thank you enough for all you've done over the years and continue to do on behalf of the CF community in New Jersey!



Pocketbook Bingo!

On November 6, 2025 friends and supporters of NJSOCF once again filled the Pompton Lakes Elks Lodge to play Bingo for designer handbags, enjoy a tricky tray and raffles, 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!"



42nd Annual Golf Tournament at Crystal Springs Golf Resort



loyal supporters, devoted volunteers and special sponsors. We thank each and every one for their commitment to this event. Special thanks to Mike Guidice who helped coordinate the event from revising menus to new contests on the course. Without Mike we wouldn't have achieved such an amazing success. We also give special thanks to Philip Luppino of V.A.L. Floors, Mike Weinberg and Ernst & Young, John Pierkarski of Ally Construction Services, and all the other donors and golfers who contributed to a successful event. And finally, thank you Deb DuHaime and Jeff Smith for doing traffic and weather at the awards dinner. This tradition is always so much fun

On Friday, July 25th, old friends and supporters of NJSOCF gathered for the 42nd Annual Cystic Fibrosis Golf Tournament at Crystal Springs Resort in Hamburg, New Jersey.

This year's event was sold out with 140 golfers teeing off at Wild

Turkey Golf Course, and another four foursomes playing at Ballyowen Golf Course. Golfers enjoyed bagels and coffee before heading out for a round of golf, followed by an open bar cocktail hour, awards dinner and raffles under the Big Sky Pavilion, at the renowned Crystal Springs Resort. We thank our dedicated committee,



New Jersey State Organization of Cystic Fibrosis

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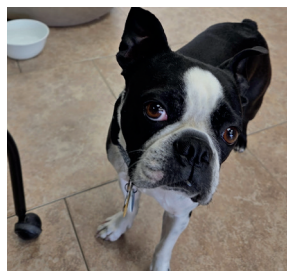
How to Donate

On-Line: a donation on line is simple and convenient. Just visit our website www.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 gifts 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.



Office Mascot, Sunny the Boston Terrier, waits for her owner at the Beauty Salon.