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That's it! It's a small step that can make a **BIG** difference!

## Special Events – Coming and Going

**2015 Bowl \*4\* Cystic Fibrosis Awareness**  
New North Arlington Bowl  
North Arlington, New Jersey  
Saturday, November 7 at 7:30 pm

**End of the Year Holiday Appeal**  
November – December 2015

**33rd Annual Golf Outing**  
Ballyowen Golf Course  
Hamburg, New Jersey  
Friday, August 5, 2016

## Special Events – In the Workings

**"Pocketbook Bingo"**  
Play Bingo for Designer Bags!  
Pompton Lakes Elks Lodge  
February 2016

**Beefsteak at the Brownstone**  
The Brownstone House  
Dinner and Tricky Tray  
April 2016

**Make Believe Mother's Day Tea**  
May 2016

## Our Mission Is ...

To help ease the heavy financial burden placed on CF patients and their families and to provide needed information.

## 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

Visit our website at [www.njsocf.org](http://www.njsocf.org).

## United Way

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

## Matching Gifts

Many medium-sized and large companies offer a matching gift program. Your employer will match you 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"

Volume 21, Number 2

Winter 2015

## Celebrating 25 years of doing what we do best!

### Nobody in New Jersey does it better!

Thirty-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.

One in 31 – more than 10,000,000—are unknowing carriers.

In addition to our special "Adult Program", NJSOCF provides services to patients from infancy onward. Aside from

"I'd like to thank NJSOCF for 19 years of support! This wonderful program has allowed me to have the proper medications, and assists me with my nutritional needs. I wish you continued success in raising awareness for CF, and appreciate your helping hands. I feel very fortunate to have this program in my life."

*Andrea Rodriguez*



the state-funded Pharmaceutical Services for Adults with Cystic Fibrosis, all of our other efforts depend on fundraising and donor contributions.

### Adult 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, with many forging careers and having families. But along with a longer life comes

A genetic disease, CF affects the lungs and pancreas. It impairs a child's natural development. It causes normal lung secretions to become thick, resulting in strains on the respiratory



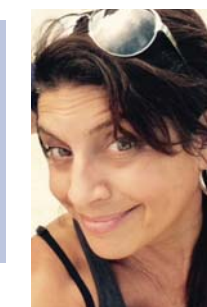
NJSOCF has absolutely been a godsend to me and my family! After working for so many years and then abruptly having to go on disability due to CF, the costs of medicines, treatments and basic life necessities, became a financial hardship on my family. My doctor turned me on to NJSOCF and I signed up in 2011. I speak to Deb and Bernice regularly and consider them my family. What they do for people with CF is amazing—they really go the extra mile.  
*Angel Figueroa*

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.

increased financial needs. Many CF patients have inadequate medical insurance and problems financing the daily costs of living with the disorder.

I am beyond blessed in all areas of my life. One specifically that I am super grateful for is the NJSOCF. I honestly don't know what I would do without the Pharmaceutical Program. We all have bills but when you have a chronic illness like CF those bills can quickly add up. My husband and I are eternally grateful for this God-sent program and the wonderful people that work there.

*Susan Pizzo*



**NEW JERSEY STATE ORGANIZATION OF CYSTIC FIBROSIS**

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Estelle recognized this change in the needs of CF patients living independently and financially on their own and decided to find ways of funding a special program for adults, now known simply as our "Adult Program."



I first came to the program in the early 90's when I had limited insurance. For many years after that, my income and insurance were good. Three years ago I had to stop working because of my CF, and the program was still there to help me and my family. NJSOCF has been a life-saver, helping me with prescription drugs, home IV's and my nutritional needs. I thank God for NJSOCF for always being there when I needed them. **Dick Quinn**

Twenty-five years ago, in 1990, after much lobbying on behalf of the CF community, the state of New Jersey began funding Pharmaceutical Services for Adults with Cystic Fibrosis. Since then, NJSOCF

**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.

We work closely with social workers at CF centers and their clients directing them toward prescription drug programs, contracting



*Ryan Frees family*

and scheduling home IV services, purchasing or renting equipment, purchasing appropriate foods and supplements, and generally assisting them with any other issues that may arise.

has helped hundreds of patients and families throughout the years.

The adult program provides financial assistance to eligible New Jersey adults age 18 and over for the purchase of prescription drugs, medical equipment and supplies, oxygen, home IV's, vitamins and nutritional supplements, and nutritious foods that are necessary for the treatment of cystic



NJSOCF has been a tremendous help to me and my family over the years. They assist with medical needs and also give emotional support. Without their help I don't know where I would be today. I have been on the Pharmaceutical Services program since 2004. NJSOCF is a wonderful organization, with a friendly and helpful staff, and I am truly grateful for their help.

**Mary Ann Gambino**

fibrosis. The program also provides up to \$500 per year towards insurance deductibles.

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!"*

# Ballyowen to Host 33rd Annual Golf Outing

NJSOCF is trying something new and exciting this year by giving all our golfers the opportunity to play the renowned Ballyowen Golf Course in Hamburg, New Jersey. The day will start with a barbeque lunch, followed by a 1 pm Shotgun Start, Cocktail Hour and Awards Dinner. **Save the Date: Friday, August 5, 2016**

We are looking forward to the private and exclusive atmosphere of Ballyowen and the benefit of having all our

golfers on one course, and together for lunch and dinner.

The New Jersey Monthly has said: "Ballyowen, the #1 golf course in New Jersey, and flagship of the Crystal Springs Resort, spreads across a treeless expanse whose rippling fairways, rugged mounds and deep swales bring Scottish links to mind and make each hole visually memorable and uniquely challenging."

## Memories From our 32nd Annual Golf Tournament



## Casino Night was fun for all!

Our first-ever Casino Night, held at the Pompton Lakes Elks Lodge last May 15, drew a fun-loving crowd that enjoyed casino games, prizes, beer, wine and food, along with lively entertainment provided by the Hott Mott Rhythm and Blues Band.



Local organizers included Catherine Daly of Pompton Plains, who lost her son, Wesley Purves to CF in 2013. "We had been thinking about holding a Casino Night for some time and are glad we got such a positive response and were able to provide a fun-filled evening while raising money for our special cause," said Executive Director Debra Sikkema.

