



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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Volunteers Mean Everything!

"Judy and Kevin Hill do it for Kirk"

Judy Hill's son, Kirk, was born in Jersey City on August 8, 1970. He was diagnosed with cystic fibrosis when he was two months old. "The hospital immediately sent Kirk by ambulance to Columbia Presbyterian Hospital in New York City," Judy said. "While we were at the hospital my two other sons, Keith and Kevin, were also tested. Fortunately they did not test positive for the CF gene."

While Judy was spending time in Columbia Presbyterian with Kirk she met Tom Fern a dad who also had a CF child. "Tom talked to us about the CF Foundation which was the only organization at the time. I met other parents there and learned much from them. The CF Foundation directed their funds to research at that time. But as Kirk got older I began to need help with the expenses of his medication and medical equipment," she said.

In 1977 the clinic at Columbia Presbyterian was moving half of its staff to St. Vincent's Hospital in lower Manhattan. It was closer for Judy so she began to take Kirk there. "Amazing as it sounds now, they were short physical therapists so my son Keith and I volunteered to do therapy (clapping and percussion therapy) on patients for a short period of time. It was there that we met George McDermott, a CF patient. That's when we also found out that Estelle Sikkema had started an organization to assist individuals with CF and their families. I decided to join them and help raise funds for NJSOCF."

"We were involved from the beginning helping out with George's softball events at the Gunnell Oval Stadium in Kearny and other locations in Kearny and North Arlington. We sold hot dogs and Kevin umped for the teams," Judy said. "George and Kirk became fast friends and pulled many epic pranks at the hospital when they were together. It was George who



Kevin and Judy Hill with Bernice DeMeritt

suggested that Kirk become involved in the North Arlington Volunteer Emergency Squad and Kirk became an EMT driver."

Judy realized that Kirk needed help with his nutritional needs and his medical equipment. "I found out quickly that the organization is for helping the patients and their needs. Kirk had a budget for nutritional supplements and nutritious foods, and when he needed a special high caloric drink that we couldn't afford, it was shipped to Kirk. The organization purchased nebulizers and helped out with Kirk's Vest as well." Judy said, "They became his angel of help for the rest of his life."

Judy remembers Kirk asking many times if she and her sons would continue to support NJSOCF if anything happened to him. "I promised him that I would. My son passed away on June 19, 2012 and Kevin and I kept our promise."

Continued...



Continued from Page 1

Over the years Judy and Kevin took part in as many special events as they could. “We help in any way we can to support the organization and the families,” she said. They brought dozens of guests to the annual fall extravaganzas, helped at softball events, tricky trays, casino nights, Pocketbook Bingo, Mother’s Day Tea campaigns and, of course, the annual Bowl For CF Awareness. This event is held in North Arlington every year, and organized and hosted by George McDermott.



Kirk on the right with George McDermott at Bowl 4 CF Awareness fundraiser in North Arlington

This year Judy and Kevin lost a dear friend of their family, Billy Salisbury. “Billy and his fiancée, Tabitha Gabriele, always supported NJSOCF at the bowling lanes. Each year Billy came and donated as much as he could, even when he was very ill,” Judy said. “This year is no different. Tabitha’s father, James Gabriele, generously donated \$10,000 in memory of Billy to help CF patients and their families in New Jersey.”

“I wish to thank Mr. Gabriele from the bottom of my heart and let him know how much this donation means to all the CF families, and to me and my family. Our prayers go out to you and God Bless you and your family for this beautiful donation.”

This year Judy and Kevin began painting for CF. They paint free-hand and with stencils all kinds of subjects including pets, football and other sports teams, Disney characters, movie stars and just about anything else you would want. “We continue to take orders and I love doing it for CF. I also crochet and do other crafts,” Judy said. “It helps me and it helps CF families too.”

As in the many years past, Judy and Kevin will be at George’s Bowl for CF Awareness event this November 16 and helping out at Pocketbook Bingo the week before. Judy and Kevin do what they do best, volunteer and make a difference for CF.

In Memory of William M. “Billy” Salisbury

Billy was a friend of the Hill boys—more like family than just a buddy. They fished together, they hunted together, went rafting, played paint ball, and took road trips to Atlantic City— they were always together. The two families shared life in Jersey City around St. Paul’s Church.

Billy found the “love of his life” when he met Tabitha Gabriele. The two of them became a fixture at CF events with the Hill family.

Billy passed away July 1, 2019 at the Memorial Sloan Kettering Cancer Center in New York at 49 years old.

NJSOCF would like to take this opportunity to thank Mr. James Gabriele for his generous donation of \$10,000 in memory of Billy.

You can rest-assured Mr. Gabriele that your donation will be used to assist the CF community in New Jersey. NJSOCF’s programs have become a virtual life raft for many individuals and families who have come to depend on us for help with the daily challenges of living with cystic fibrosis.

On behalf of all the CF individuals and families we help, thank you from the bottom of our hearts!

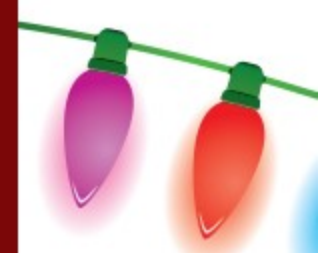
How to Donate

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 loved one.

MATCHING GIFTS: Your employer will match your personal donation with an equal amount.

UNITED WAY: Employees can participate in payroll deduction program at work.



36th Annual Golf Tournament

NJSOCF's most prestigious event of the year proved to be another success. On August 2nd beautiful weather was key to a fun day on the golf course, followed by dinner at Crystal Springs Golf Club.

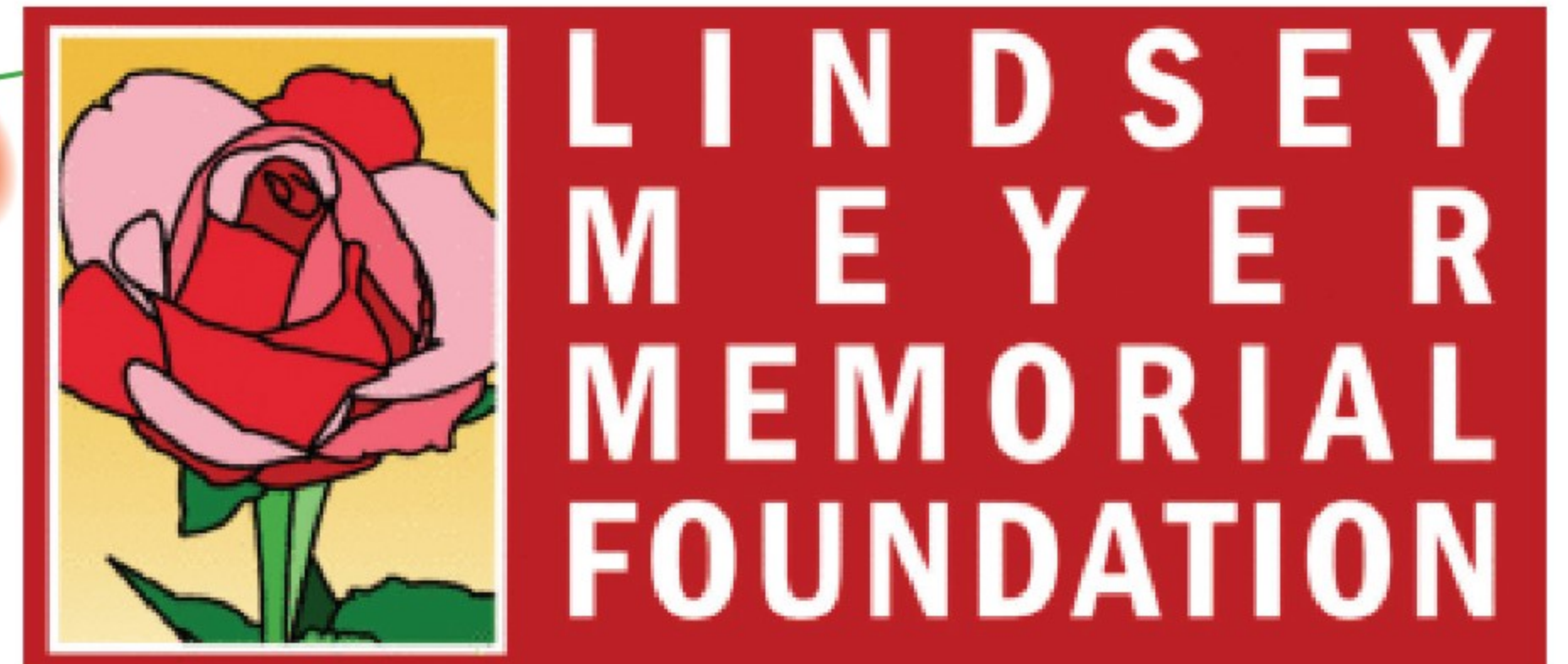


“Pocketbook Bingo!”

Nothing spells “success” like Pocketbook Bingo! On November 7th over 200 supporters attended the event at the Pompton Lakes Elk Lodge to win one of twelve designer handbags. “Smiling faces say it all at a night of fun and games, beautiful handbags and tricky tray prizes,” said Executive Director, Debra Sikkema.



Lindsey Meyer Memorial Foundation makes \$5,000 donation to NJSOCF!



The Lindsey Meyer Memorial Foundation (LMMF) is a non-profit organization based in Rutherford, New Jersey. LMMF was established to celebrate the life, love and laughter of Lindsey Rose Meyer. Through programming and fundraising efforts, we seek to provide youth with opportunities to thrive.

“The Lindsey Meyer Memorial Foundation has been honored to support the New Jersey State Organization of Cystic Fibrosis for many years. NJSOCF has been an incredible support to individuals with CF which provides them an opportunity to lead full and productive lives. We are so grateful to Debbie, Bernice and the entire NJSOCF for all they do.”

This year marks the 10th Annual Beefsteak Dinner at the Brownstone hosted by LMMF to support the organizations that meant so much to Lindsay.



Wayne Meyer speaks to supporters at the Annual LMMF Beefsteak Dinner at The Brownstone

Lindsey battled CF until 2001. She never let her illness interfere with her love and zest for life. She was passionate about helping teens realize their leadership potential and to create positive changes in their lives. LMMF supports the Lindsey Meyer Teen Institute, a program, reborn with Lindsey's name in 2005.

“I'd like to thank Wayne Meyer, Eileen Baker and everyone else involved in the LMMF, and of course all of their supporters for the generous donation to NJSOCF,” said Debra Sikkema, Executive Director.

New Vertex cystic fibrosis drug offers hope to CF patients

By Dave Berkenbush

With new 21st century advances in CF drug modalities, Vertex has been a leader in CF gene therapy drug treatments.

Only five or so years ago, Vertex introduced one of the first CF gene defect therapy altering drugs Orkambi. This drug was limited to only a few CF mutations (double D508 only), a small population of CF patients, however, it ushered in a new era in CF drug treatment therapies. Shortly thereafter, three or so years ago, a second Vertex drug—Kalydeco—was introduced. At first it was targeted to the D508 and only a few secondary genetic defects. It was so widely successful that 2 years ago it was released to a far greater number of secondary genetic defect patients, resulting in a far greater number of CF patient qualifiers.

Kalydeco's results for the average CF patient could expect a 2-5% improvement in overall lung function with only a less than 1% annual lung function decline.

Shortly thereafter, about one and a half years ago, Vertex released Symdeco. Although very successful, it was only available to D508 and a limited number of secondary genetic defect candidates.



WWW.TRIKAFTA.COM

Sooner than expected, in the fall of 2019, Vertex released an FDA approved CF therapy drug called Trikafta, a triple combination therapy that treats the underlying cause of CF. With this new breakthrough, Trikafta will not only be available to the double D508 CF patient community, but also to almost all patients with a least one D508 and any secondary genetic mutation. This means that almost the entire CF patient community can now benefit from this new drug.

Trikafta is expected to provide up to 6-10% increase in total CF lung function with only negligible, if any, annual lung function decline. It will also increase nutritional absorption. This new drug not only improves the quality of life for CF patients it also provides new hope to virtually the entire community.

For more information on this drug and Vertex Patient Support you can visit: www.trikafta.com



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Meet Sunny the office mascot. Sunny, a Boston Terrier, was born in Lancaster, Pennsylvania. She is learning that to be an office mascot means you must be friendly and cheerful at all times. Sunny is on the road to be the ultimate office mascot!