## 41st Annual Cystic Fibrosis Golf Tournament

at Wild Turkey Golf Club

Friday, July 26th once again brought together old friends and supporters of the Annual Cystic Fibrosis Golf Tournament at Crystal Springs Resort in Hamburg, New Jersey.



vear marked 41st Annual Golf Tournament Mother Nature rewarded us with a beautiful sunny day. 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. Everyone enjoyed

bagels and coffee before heading out for a round of golf, followed by an open bar cocktail hour, awards dinner, raffle and 50/50. This all took place under a magnificent tent, the Big Sky Pavilion, at the renowned Crystal Springs Resort.

An event as successful as this cannot happen without a hard tent of the control of

An event as successful as this cannot happen without a hard working committee, loyal supporters, devoted volunteers and special sponsors, and 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!



# New Jersey State Organization of Cystic Fibrosis

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## **HOW TO DONATE**

<u>ON-LINE</u>: Making a donation on line is simple and convenient. Just visit our website—www.njsocf.org

<u>MEMORIAL GIFTS:</u> 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.

<u>MATCHING GIFTS:</u> Many medium-sized and large companies offer a matching gift program.

<u>UNITED WAY:</u> 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, enjoys summer in the sunshine.



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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!

#### **Contact Us**

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## Julie and Sal Finocchiaro

"Stepped back, took a deep breath and worked through the situation."

Sal and I met at work in 1987. We married in 1992 and had our first child three years later. Things was good for us, we traveled and didn't have a care in the world. But life has its' twists and turns and when our second child Julianna was born in 1998, there was something different about her. She had a persistent cough that didn't seem to go away.



The Finocchiaro Family

We went from doctor to doctor and they could not determine what was wrong. No one at this time thought it was cystic fibrosis, until our third child Justin was born in 2002 with cystic fibrosis. Our doctor immediately told us to get all of our children tested. Low and behold, Julianna was diagnosed with CF as well. Now that would explain the persistent cough she had throughout those days.

Faced with that news, Sal and I were devastated. We read all the information we could get our hands on about cystic fibrosis, and that even scared us more. How could we have two children with the disease? We knew that we had to do whatever we could for our children, so we needed to step back, take a deep breath, and work through the situation as best we could. So that's exactly what we did. We reached out to different CF facilities and found one that best worked with our family.

We didn't know about the New Jersey State Organization of CF just yet, but God had a plan and we were about to find out.

My husband happened to be at a neighbor's wake one day, and there was a woman sitting behind him talking about cystic fibrosis. He couldn't help overhearing her speaking about the disease. Sal approached the woman and introduced himself telling her about our two children with CF.

The woman he met was Bernice De Meritt, a niece of the woman who passed away. Sal and I called the woman Aunt Betty too because she babysat our oldest son Salvatore. When Sal met Bernice we felt that it was no coincidence, but rather divine intervention.

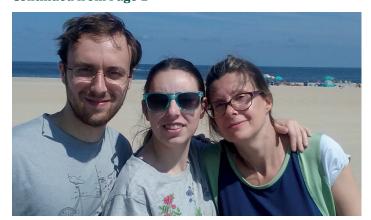


Justin and his Dad

Bernice told my husband about the Organization and how they help CF families in New Jersey. This was God at work and from then on my husband and I got fully involved with the Organization. They were able to connect us with other families that had CF, which helped us greatly. Sal and I decided to volunteer our time and it was the best thing we ever did. Our daughter Julianna and our

Continued...

#### **Continued from Page 1**



Salvatore, Julianna and Julie

son Justin just like many kids with CF, had hospital stays, tune ups, and many hours of chest physical therapy. There were times when it seemed very daunting and we would wonder to ourselves why us, but then I would say why not us since we were chosen to take care of our children. The routines of therapy became a part of our daily lives. As Julianna and Justin got older, they managed their own therapies, including nebulizer sterilization, ordering medications, and taking good care of their health by eating right, exercising, and getting the proper amount of sleep. Then it happened, a new CF drug came out that was targeting Julianna & Justin's specific mutation called Trikafta. We were apprehensive in the beginning for them to take this new drug, but once they started there was no going back, and their lung function improved tremendously. No more hospital stays, a lot less therapies, and just all around

improved health. Julianna can jog for a longer period of time now, and Justin can play basketball for hours at a time. We are blessed that this treatment came along. Julianna graduated from Montclair State University and is now a school teacher. Currently, Justin is in his last semester at Montclair State University, and plans to get his Nursing degree. You never know what path life is going to take you on, but whatever it is, God has a plan and it's perfect.



Julianna with her Dad at Graduation

## Office Chit Chat...

person to apply for the new "Adult" Program that NJSOCF lobbied for and was granted funding from the State of New Jersey. He received assistance until 2024 (34 years!) Dave also gave back



In 1990 Dave Berkenbush was the first to the organization by volunteering for fundraising events, mail campaigns and general office chores, earning him status as Number 1 Volunteer!

> In April of this year Dave moved to Millsboro, Delaware leaving New Jersey and our organization. He is missed by the staff and our family of volunteers. But we stay in touch!

In July Of 2023 Diane Berkenbush started to volunteer with NISOCF. With the passing of Tim Roberts that month, Diane was the perfect fit for the organization. She took over the positions of Grant Administrator and Bookkeeper at NJSOCF. Diane has 20 years of bookkeeping experience and



40 years of CF knowledge. Diane's two brother-in-laws have CF and Dave is one

Diane and her husband Rick have been married for 36 years and have two sons who are now 31 years old.

## Our Hero George McDermott!!

George McDermott of North Arlington has always been our hero. For the past thirty years George has been involved with the New Jersey State Organization of Cystic Fibrosis. His relationship with founder Estelle Sikkema began when George made a pledge to himself not to let CF ruin his life. The organization helped George and he continues to help the organization.

Over the years George has become one of NJSOCF's most loyal volunteers and fund raisers. In the past he's organized softball marathons and the annual Bowling for CF Awareness, he serves as a CF Spokesperson and is on the Board of Directors. George has been a steady force in the life of NJSOCF, and we are so proud to have him on our team!

Now George is being given the honor of 2025 EMT of the Year after 34 years of service to his community, and will be marching in the Rutherford St. Patrick's Day Parade in March 2025. As the article states George has had so many accomplishments in his life, including two beautiful daughters now graduated from college! George....you are our hero!



## 2025 **EMT** of the Year George McDermott

George McDermott of North Arlington, NJ, has dedicated his life to selfless service and community engagement. Adopted by the McDermott family, his journey of giving back began at Queen of Peace High School, where he demonstrated acts of kindness through the school's charitable group, SIGN

George's commitment to helping others led him to join the North Arlington Volunteer Emergency Squad (NAVES), where during his 34 years of service he has saved 25 lives through CPR and earned accolades as EMT of the Year. Additionally, George has served as both a Dispatcher for the North Arlington Police Department for 25 yrs and a Fire Fighter for 23 yrs, even receiving recognition as Fire Fighter of the Year for his exceptional service during Hurricane Sandy relief efforts.

A believer in faith-driven service, George is an active 4th degree Knight with Queen of Peace Council #3428 and Monsignor Peter B. O'Connor Assembly #1543. His dedication extends to public service roles, where he serves on the North Arlington Board of Education, North Arlington Board of Health and the Board of Directors of the New Jersey State Organization for Cystic Fibrosis, while also volunteering for causes like aiding 9/11 recovery operations and supporting survivors of domestic violence

As a champion for the Special Needs Community with Access for All, George's compassionate nature shines through his commitment to assisting seniors and his proud family that includes his wife Angelique and their children Chevenne, Brianna, Taylor, Dean and Lauren, George's inspiring journey showcases the impact of kindness and generosity, proving that a challenging beginning can lead to a lifetime of positive influence.

## Pocketbook Bingo... Still a Hit!



Once again the Pompton Lakes Elks Lodge was filled with NJSOCF Supporters and Bingo aficionados to play the game for luxurious designer handbags. April 25 of this year 230 attendees arrived with hopes of winning a handbag, or one of the upscale beautiful Tricky Tray prizes, or to win the

lottery tickets or 50/50 which paid out \$1,000 to the winner! Guests also brought an amazing variety of foods to nosh on before the big event.





"It seems that our supporters never tire of this event," said Executive Director Debra Sikkema. "I cannot thank our volunteers enough. They come out faithfully to help with set-up, selling raffles and boards, and general hosting of the event. Thank you for always being there for us!"