



Jane K. Dove remembered.....

Close friend and colleague, Jane Dove, passed away suddenly on March 8, 2018 at her home in northern Westchester, New York.

Jane began consulting with NJSOCF in the mid-1980's and developed the first newsletter called *Update*. After a short hiatus, the current newsletter of NJSOCF was developed and Jane interviewed, wrote and helped design every issue of *Breathe Easy*, until this one.

Jane was a no-nonsense woman of great stature and integrity. She had a wonderful wit that went along with her intelligence. Jane wrote for many publications, including WAG Magazine, and for many years kept her community aware in local newspapers.

She loved animals and especially her dogs. We have been through much together.....and Janeyou are sadly missed.

Our Mission is...

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 is...

We help them breathe easier!

How to Donate

On-Line Making a donation on line is simple and convenient. Just visit our website—njsocf.org.

Memorial Gifts

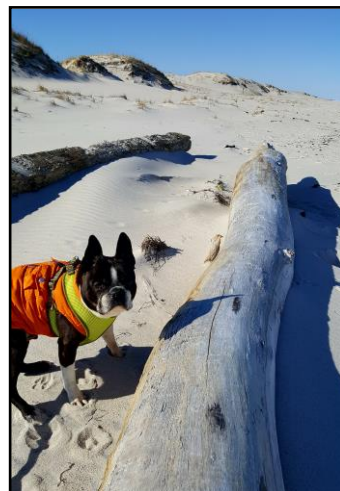
A memorial gift to NJSOCF makes a lasting tribute to a departed loved one. A special occasion gift can be used to celebrate birthdays, anniversaries, and even be given in lieu of wedding favors.

Matching Gifts

Many medium-sized and large companies offer a matching gift program. 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.



NJSOCF Mascot, Mickey eyes a large piece of driftwood on Island Beach State Park.

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FUNDRAISING EVENTS RAISE CF AWARENESS

Traci Montelbano: Run and Walk for Cystic Fibrosis!

Seventeen year old Traci Montelbano of Warwick, New York wanted to do something significant for her senior project at Warwick Valley High School. She chose to raise awareness for cystic fibrosis and created a "Run and Walk for Cystic Fibrosis!"

The Senior Project, an independent study program, was to create an event for a non-profit. Traci plans to attend SUNY New Paltz next year to eventually become an occupational therapist, and she already has some experience with non-profits. She's been involved with the Lindsey Meyer Memorial Foundation for most of her life.

The Lindsey Meyer Memorial Foundation was established to "celebrate the life, love and laughter" of Lindsey Rose Meyer, who lived with cystic fibrosis until she was a senior in high school in 2001.

"I was only two years old when Lindsey passed away from cystic fibrosis so the charity is near and dear to my heart," Traci said. "I've been to every fundraiser the Lindsey Meyer Foundation has put on, all the Pumpkin Runs and Beefsteaks. My family is very close friends with Wayne Meyer and Eileen Baker, and everyone else involved in the foundation over the years."



The 'Run and Walk' took place on April 14th, a beautiful Saturday morning. Supporters gathered at 11:00 a.m. for a 1 mile walk or 2 mile run at the Warwick Valley High School Track. The \$10 entrance fee got you a T-shirt memorializing the event. Runners went first running 2 miles around the track and walkers walked the one mile. There was a sense of goodwill throughout the event and many new friends were made.



Traci Montelbano

An after party took place at the Blue Arrow Farm in Pine Island where a wonderful lunch was presented and many dishes were donated by local businesses.

The New Jersey State Organization of Cystic Fibrosis is proud and grateful to be the recipient of \$1,800 raised at Traci's Senior Project event. Thank you Traci.....it was an exceptional day!

Special Events coming and going.....

"POCKETBOOK BINGO"

On November 30, 2017 over 340 people filled the Pompton Lakes Elks Lodge to play bingo for designer handbags and raise awareness for cystic fibrosis. NJSOCF's third *Pocketbook Bingo* was another huge success and a great time was had by all!



"PUNK! V.S. FIBROSIS" 2018

It started when Mike Normann, drummer for *The Jukebox Romantics*, wanted to pay tribute to his cousin Steven Sileo who passed away at age 23 in 2008. Mike and his production company Punk! V.S.Fibrosis sought to raise awareness for CF by donating a portion of the proceeds from his punk rock shows to charities, including NJSOCF.

They recently released a 29 song compilation, "Bunco Llama Volume 1" donating all the proceeds to NJSOCF in memory of Steve, while raising awareness for CF!!

"MAKE BELIEVE" MOTHER'S DAY TEA PARTY 2018

Tried and true our annual "Make Believe" Mother's Day Tea Party gives our supporters a chance to reach out to friends and family to remind them that there are people who need a little kindness. Mother's Day is a perfect time of the year to reflect on individuals with CF whose life challenges them each and every day.



Coming in 2018

SAVE THE DATE!! Old friends, a beautiful course and scenic views—Crystal Springs never disappoints. So plan to support our 35th Annual Golf Tournament and be a part of this wonderful tradition.

35th Annual Golf Tournament

Friday, August 3, 2018

Wild Turkey Golf Club

Hamburg, New Jersey

For More Information:

Call NJSOCystic Fibrosis at (973) 595-1232

or email das@njsocf.org



Visit our website for more information on Special Events www.njsocf.org

TRAVELING WITH CYSTIC FIBROSIS

In today's complicated world, traveling and preparing to travel can be a daunting task, even for the healthy. We've all experienced the nightmare of pre-flight security procedures at the airport, and now add the complication of a medical condition like cystic fibrosis, and there are numerous things to consider and prepare for. Personal experiences can shed light on these concerns and issues that can help avoid some of the inevitable pitfalls.



Doug Lee and Cassandra on the East Coast of Ireland

DOUG LEE at 33 has dealt with CF his whole life, but it certainly hasn't stopped him from traveling, even now two years post-op lung transplant. His travels have taken him to Europe – Britain, Scotland and Ireland. Doug has also traveled extensively here in the United States. While he was in Southern California he drove up the West Coast all the way to Oregon. And most recently he visited Montana. Doug traveled with a duffle bag for his portable nebulizers and CF medications. He also carried a portable percussor since it was easier to carrying on flights than 'the Vest,' even though it was more complicated to use. Doug said, "It was a trade-off." Before his transplant, while on his California trip, Doug also needed a portable O2 compressor, but he found out the hard way that it's no longer allowed on flights for safety reasons. His airline did provide a

condenser that he used while on the flight. Having to store all these things below the seat in front of him made his flights extremely uncomfortable. Doug said, "It made me literally squished in my seat with no room for my legs." Fortunately for Doug, post lung transplant, he no longer has to contend with compressors, nebulizers and percussors. He's now replaced one set of CF related drugs – Pulmozyme, inhaled anti-biotics and Albuterol with a new set of anti-rejection drugs, and he travels more comfortably than before.

DAVE BERKENBUSH, traveling with the same concerns and issues, recently flew to Ft. Meyers, Florida. He traveled with three portable nebulizers and CF medications, Pulmozyme, Cayston and Abluterol, as well as 'the Vest.' Dave made pre-flight arrangements with his airline to travel 'handicapped' to allow early boarding and figure out equipment logistics on the plane. On his flight down to Florida, the stewards were very helpful and courteous and assisted him by stowing 'the Vest' in the forward galley. But on his return flight from Florida, Dave said, "I was literally on my own. I had NO place to stow 'the Vest' other than in the overhead compartment. It was heavy to lift, and it barely fit in the overhead bin," he said. "The lesson learned is that your flight crew determines your experience."



Dave Berkenbush with Debbie DuHaime

There can be pit-falls to traveling with CF, so one has to always prepare in advance for the unexpected. But, it can be well worth the effort for the overall exciting experience of travel.

Planning ahead before your trip will help prevent problems during your excursion.

- Be sure to list all medications, (including mini-coolers for long trips) oxygen and equipment, i.e., nebs, masks and 'The Vest.' This will aide you as you prepare for your journey.
- Contact your healthcare provider (CF clinic/doctor) to submit clearance well in advance to the airline for early boarding.
- Research the closest healthcare providers at your destination as a precaution to any medical emergencies that may arise during your trip. It could be a life-saver.