



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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NICOLE BIUNNO: "LIVE TO INSPIRE"



By Nicole Biunno

It all started with a dedicated science teacher in 8th grade which would bring me down the road to having a love for science. Mrs. Lato taught chemistry at St. Rose of Lima in East Hanover and made the classes always interesting. I was valedictorian in my 8th grade graduation class and continued on to Academy of Saint Elizabeth for my high school years and enjoyed my science classes.

Graduating in 2010, I was accepted to Seton Hall University majoring in chemistry. I chose to live on campus freshman year and commuted for the next few years where I would be working on campus part-time in a lab. I graduated from SHU in 2014 with a chemistry degree where I contemplated continuing my education in chemistry or applying to a pharmacy program. I decided to take a year off so I could work; save money and study for the PCAT's (Pharmacy College Admission Test) researching local colleges with pharmacy programs. I visited Rutgers and Fairleigh Dickinson University which recently added a pharmacy program in New Jersey. After seeing FDU's campus, I immediately fell in love with the school, and the location was a bonus. I applied for admission and was accepted into the four-year pharmacy program at Fairleigh Dickinson in Florham Park. To say the least,

an additional four years of study was not easy, especially dealing with cystic fibrosis and the daily regime to stay healthy. I would also need to be on top of studying for exams every Monday while working weekends at Walgreens, making time to work out at the gym, as well as maintaining a social life. At times, I questioned if this is the right decision and if I was capable of this line of work, but one thing I stand by throughout my life is to never give up. My dream was to always work in the medical field, and I was not going to give up that easily. My parents were behind me 100% and were my inspiration to continue on during tough times of not feeling my best. They ensured my student grad loans were processed each year.

My dad is my #1 supporter (Mom too) and loves to take care of me and my brother Nicholas who is severely anaphylactic to many foods. My dad has flexibility with his job so he loves to cook and delicious dinners are made every night. He always made sure I had a good lunch so I would not lose any weight. I am forever grateful for the support of family, my boyfriend of 9 years, and my friends during this tough journey, as well as grateful for the special friendships I have made in pharmacy school.



Nicole and her dad, Nick Biunno

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After three years of didactic courses and one year of clinical rotations, I completed my pharmacy courses on March 15, 2019. I continue to study until graduation to pass the board exams and earn my pharmacy degree. With graduation drawing near, I continue to think into the future about my ultimate goals, and whether I want to pursue becoming a clinical pharmacist or working in the industry as a part of a research team. The opportunities are endless.

My motto has become “Live to Inspire” and one day people will say, because of you, I didn’t give up.

FROM MOM AND DAD, MARGARET AND NICK BIUNNO

By Margaret Biunno

Nicole has always been an inspiration to her family and friends in all her achievements and daily health challenges. Nicole was diagnosed at three years old with CF and, at that time, we were told she would never play sports. Throughout her middle and high school years, she was very involved with sports and excelled in school. Our daughter is one strong, determined young woman who has overcome so many obstacles throughout her life and has always made her health a priority but also lives her life. We have been blessed these past 25 years with the Pediatric and Adult doctors at Morristown Medical Center who always took great care of Nicole’s health. We are so proud of all her accomplishments and she is a true role model of what can be achieved in life while facing challenges.



Mom, Margaret with Nicole

Soon, she will be wearing the “white coat” signifying a pharmacist and will be known as “Dr. Biunno.” Many tears will be flowing on graduation day but tears of joy and celebration after eight years of study. As we have always told Nicole, believe in yourself and anything is possible through hard work, perseverance and faith in God. Fulfill your dreams and be happy. Make every day count!

Lastly, we have to thank the New Jersey State Organization of Cystic Fibrosis for guiding our family 25 years ago when my sister-in-law made a call to NJSOCF from the Yellow Pages asking for guidance when Nicole was first diagnosed. That voice guiding us for many years after was Estelle Sikkema. How blessed we were when she answered that phone!

SPECIAL EVENTS COMING IN 2019

36th Annual Golf Tournament – August 2nd

Pocketbook Bingo – November 7th

Bowl for CF Awareness 80’s Night – November 16th

Visit our website for additional events and more information www.njsocf.org

NJ TRIED TO YANK GRANT FOR LIFE-SAVING CYSTIC FIBROSIS MEDS; SHE FOUGHT BACK

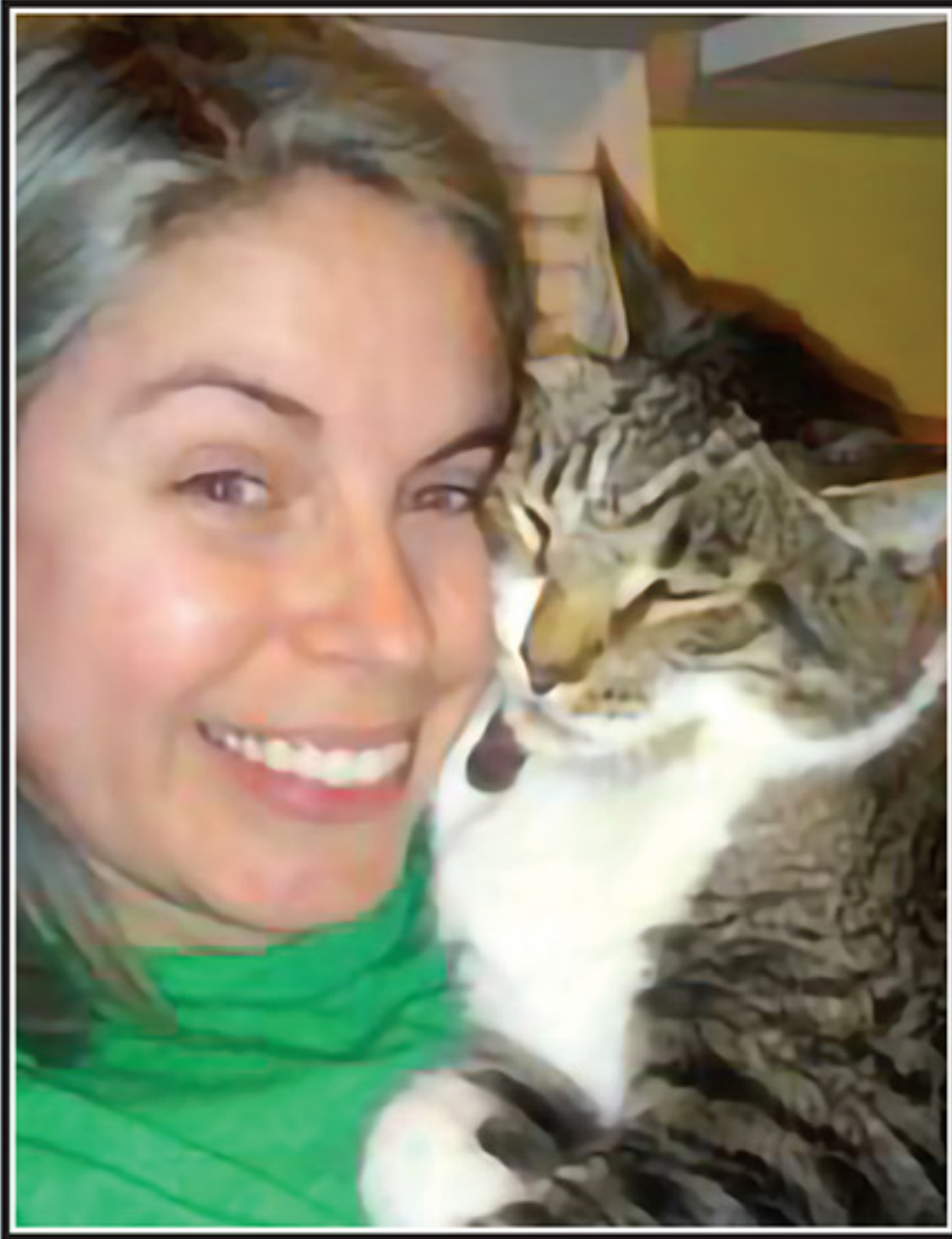
By Jerry Carino, Asbury Park Press, April 12, 2019

Middletown's Jenna Flaherty became an advocate out of necessity. 'Cutting this funding would be devastating.'

Each day, 37-year-old Jenna Flaherty takes 12 pills and four different inhalers. She also does breathing exercises.

This is how you deal with cystic fibrosis. You fight the progressive lung disease using every tool available.

"I know I can't get rid of it," she said, "but in my head I'm going to beat it."



Lately, the Middletown resident, who works as a veterinary technician at Atlantic Highlands Animal Hospital, found herself battling another obstacle: New Jersey's government. A grant that helps defray the cost of her medication co-pays fell into the crosshairs of state budget bean counters.

The grant, which has been on the books since 1990, saves Flaherty about \$2,000 a year. Imagine getting hit with a \$2,000 surcharge for the right to breathe. That's the gut-punch Flaherty faced, so she added a new tool to her regiment: advocacy.

She pushed back, reaching out to lawmakers and enlisting friends and relatives to do the same. This was new territory for a relatively private person. Her previous claim to fame was being the Guinness-certified owner of the world's oldest rabbit, which lived to 17.

"I like to lay low," Flaherty said. But when this happened it was, "No, you're not going to forget about us."

Always on the chopping block

Cystic Fibrosis is a genetic condition that causes lung infections and makes it hard to breathe. Ultimately, it ends in respiratory failure. But progress in treatments has doubled the median life expectancy over the past few decades.

With CF patients now living longer, the cost of medication is an increasingly urgent matter. Carl Lind saw this coming. In 1990, the Point Pleasant Beach High School graduate was instrumental in securing the grant in question, named Pharmaceutical Services for Adults with Cystic Fibrosis.

Lind battled cystic fibrosis until his death in 2003 at age 43. The grant, which is disbursed by the nonprofit New Jersey State Organization of Cystic Fibrosis (NJSOCF), aids 200 beneficiaries each year. The total appropriation is less than \$400,000, which is a drop in the state's bucket. Yet the Totowa-based NJSOCF is no stranger to this tug of war.

"A few times we've had to go through these machinations," executive director Debra Sikkema said. "You're always a little nervous with a new administration, that they have no idea what this is about. It seems like it's always on the chopping block when they want to cut the budget."

Last month, she said, "It was threatened big-time."

In a letter to Gov. Phil Murphy, Sikkema noted that the grant "is the only source for financial assistance to the adult CF community in the state" and "in some cases, the services we provide literally make the difference between a longer life and an earlier death."

Last week, the NJSOCF was assured that the grant will be reinstated. But this is New Jersey, the epitome of government dysfunction. Everyone is a little on edge until the funds get delivered.

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In the meantime, Sikkema is impressed by how far Flaherty and other outspoken patients advanced the cause. "It's amazing," she said. "If it weren't for them, this might have fallen through the cracks."

A fight for their lives

Flaherty was diagnosed with cystic fibrosis at age 12, which is late. She's been hospitalized 10 times over the years with complications, most recently for pneumonia last August.

"CF not only affects your breathing, it affects your mental state," she explained. "There are good days when you feel like you can run, and then you can wake up the next morning and a flight of stairs looks like a mountain."

The steroids that help Flaherty's lungs take a toll on her bones. She underwent spinal fusion surgery in 2016 and

will need a double knee replacement in the near future. Aside from sporadic coughing fits, though, a stranger would never know at a glance what ails her. That's part of the challenge in raising public awareness.

"It's difficult for people who don't have CF to see somebody who looks pretty normal and understand what's going on inside your body." She said.

The recently released movie "Five Feet Apart," which depicts the obstacles to romance between two cystic fibrosis patients, will help. Ultimately, though, Flaherty has become her own best advocate.

It's a bit outside her comfort zone, but the stakes couldn't be higher.

"Cutting this funding would be devastating," she said. "It's almost like we're fighting for our lives here. I don't know why we have to do that."

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.



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