



BREATHE EASY

New Jersey State Organization of Cystic Fibrosis

Established in 1977

"We are the ones who help them breathe easier"



Volume 29

Number 2

Winter 2020

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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In Sickness and in Health

"Nicole Kohr realizes her dreams."

Nicole Kohr is a cystic fibrosis patient from Somerset County, New Jersey. Nicole and her fiancé at the time, Jared, had a beautiful "Disney's Up" themed wedding planned for June 1, 2019. Little did they know that Nicole's CF would take a turn for the worse and she would end up in the care of the Hospital of the University of Pennsylvania's lung transplant team.

Just days away from the wedding Nicole and Jared had to make a tough decision; should they list her for lung transplant immediately, or should they proceed to have the wedding of their dreams. They chose both!

Dressed to the nines, the "69" roses some might say, Nicole and Jared, and her oxygen tank (referred to as O2D2) made their way down the aisle. With a 28% FEV1 lung function, which fell to 11% a few days later, Nicole and Jared danced the night away. Thirteen days later on June 13 at 11:00 pm, Nicole received a double lung transplant, met under the categories of lifesaving and quality of life. The family waited 11 hours to hear the words, "she made it!"

With new lungs and a new lease on life, Nicole and Jared, and Nicole's mom Patty enjoyed the first part of the newlyweds' honeymoon at the Gift of Life, a long-term residence where transplant patients and their families can stay while they receive transplant-related care. Nicole's mom, Patty, was very emotional at the sight of her frail, but now breathing, 26-year old

daughter. "She was always a firecracker of animation and happiness, an inspiration to all of us," Patty reminisced. "Watching her go from dancing around the living room to lying helplessly on our couch was heartbreaking. But I just watched her blow a balloon for the first time in ten years, and it was like watching a miracle unfold before my eyes. I feel like I have my Nicole back."

Post-transplant, Nicole and her family received a lot of love and praise on social media. Known for her Twitter handle @cystic4real, and her Instagram @sigurn1, the outpouring of love inspired the family to make all of Nicole's post-lung transplant care public.

"I was never public about the fact that I had cystic fibrosis. Most of my friends didn't even know that I was sick, and if they did, they did not know the extent. I felt like people would treat me differently and I wanted to be known first and foremost as a performer. I'm still proud of that decision, but I am also thankful for how supportive social media has been since I revealed my secret identity.



Nicole and mom Patty at her wedding

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I like to think of it as a behind the scenes tour of my life as a performer with CF.”

Post-surgery Nicole spent seven weeks in outpatient rehabilitation. She has also overcome minor complications and life changes related to new lungs, including an entirely new treatment plan and even more doctor visits.



In addition to cystic fibrosis, Nicole also suffers from gastroparesis, P.O.T.S., endometriosis, severe hearing loss, osteoporosis, and is at a higher risk for diabetes. Due to her two rare mutations, she continues to navigate different issues resulting from a life with CF.

“I am so thankful that I’m able to breathe. I can spend time with my husband, my mom and return to the world of musical theater. Team Transplant!”

important. As moving as it is hilarious, this show will tug at your heart strings and tickle your funny bone.

The creative team, comprised of cystic fibrosis patients and advocates, is spearheaded by cystic fibrosis patient Nicole Kohr. Nicole, the writer and executive producer, is on a mission to bridge the gap between the chronically ill and theater communities.



Sofia Solimando plays Gabriella Michaels in Fall Risk

“I contacted the Cystic Fibrosis Foundation shortly before my bilateral lung transplant in 2019 because I was having trouble getting anyone to read my musical,” Nicole said. “I was in hysterics on the morning of my wedding, June 1, 2019, when I received an email saying my team and I received one of five Impact Grant Awards from the CF Foundation. I was transplanted fourteen days later. It was my own Cinderella story.”

A staged reading, a preview of the script before a live audience, was set to appear on stage on May 2, 2020. Due to the COVID-19 outbreak and the safety of the cast and crew, the team moved their production online. On June 20, 2020 the “Fall Risk” cast performed a livestreamed staged reading of Act One over YouTube for an audience of 1.7K viewers, and the feedback was inspiring.

“I was inspired by the lyrics,” said one of “Fall Risk” composers Mike Morris, Dance Arranger for “Big! The Musical” (National Tour) and a father to a cystic fibrosis patient. “It’s been a labor of love contributing to this piece.”

Fall Risk, the CF Musical Comedy CF Foundation Impact Grant Recipient



Nicole Kohr with Nicole Dvorin, Producer of Fall Risk

“Fall Risk”, a new musical comedy about cystic fibrosis, has come a long way since its start in 2018. Based on a true story “Fall Risk” chronicles Gabriella Michaels, a quirky actress and cystic fibrosis patient, on her journey through a bilateral lung transplant evaluation. Things grow complicated when Gabby receives an unexpected callback for a regional theater production. Now it’s up to her family, her doctor, and her director to convince her which is more

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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“As a Cfer, the marriage of humor and the difficulties of living with a chronic illness is perfection. I laughed. I cried. I’m praying for an encore,” said Michele M, a livestream viewer.

The team has since been nominated for 2 team WEGO Health Nominations and eight individual nominations. “Fall Risk” received a second grant from the CF Foundation. They even performed live at BreatheCon 2020, but they’re not done yet. The creative team spent the last 6 months revamping the storyline and the music. Now, they need your help to perfect draft two.

“In an attempt to remain loyal to our mission of inclusivity and accessibility, we will keep all of our rehearsals, workshops, and performances online,” said Music Director and fellow cystic fibrosis patient Adam Brostowitz. “With that said, we’d like to provide more remote tools and opportunities to our participants and that way anyone can participate or view the show from the comfort of their home.”



Production of Fall Risk goes online after COVID

The team is in search of pro bono work from lawyers and accountants, volunteers, and sponsors. All work is done remotely. Auditions for upcoming workshops and performances are also posted on the website in real time. Navigate to fallriskthemusical.com and submit an audition for a chance to work with the team! Remember to follow them on social media as well @fallriskmusical, or email any questions to fallriskmusical@gmail.com. In unprecedented times like these, every little bit helps, because everyone is a fall risk.

37th Annual Cystic Fibrosis Golf Tournament *“Fun and Sun in October”*



Originally set for July 31, our biggest fundraiser of the year was COVID-cancelled! Even though we penciled in an October date we still faced uncertainty. When we realized that golfers can’t be kept down and the courses were finally open for business, we decided to go forward on October 9th.. And what a day it was! Thanks to our wonderful volunteers, our generous sponsors, brilliant sunshine, and loyal golfers who filled the course to capacity, our 37th Annual Golf Tournament was the most successful in years!





Human Kindness

Mike and Heather rely on new friends and neighbors to get through COVID lockdown

Michael wasn't very public about having cystic fibrosis before this past March, only three of his neighbors were even aware. But this all changed once COVID started. Mike and Heather had to keep their distance when walking their dogs Royce and Bentley in the neighborhood and couldn't let anyone get close enough to pet them. CFers are very high risk for COVID and neither Mike nor Heather could go to the stores or anywhere else for that matter.

When COVID lockdowns started Mike and Heather had only one food store nearby that would deliver, but wait times started to become weeks. They ordered whatever they could online and had to Lysol all the boxes and even the mail. When they started to run low on Lysol Heather asked Michael if she could post their story on the town's Facebook page. Within an hour she had 23 replies, including their dog walker who said he would have a can of Lysol on their steps in 15 minutes! Since then their dog walkers have reached out many times to check on them to see if they needed anything. Even a complete stranger, whose cousin had CF, dropped off a few bottles of Lysol and wipes the next day, and wouldn't let them reimburse her. Their veterinarian, who lives two doors away, dropped off Bentley's medicine (he is epileptic) and she came and clipped their dogs' nails in the garage. Others did food shopping and helped out with other essentials.



Michael with Royce and therapy dog Bentley

Mike and Heather feel blessed for old and new friends, their family, and their neighbors who really kept up and checked up on them throughout this difficult time. Having CF requires extra precautions, and they are grateful to everyone who selflessly offered their help, and most importantly, they are grateful for each other.

Michael is 45 years old and was diagnosed with CF at 2.5 years old. He has been dating Heather for four years and they moved in together two years ago. Their two dogs, Bentley and Royce, are their fur babies and have also been a huge blessing throughout the last 8 months.



New Jersey State Organization of Cystic Fibrosis

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NJSOCF Mascot

Sunny enjoys a piece of driftwood from the beach.