

Continued from Page 1

“We were evicted from our apartment last year and moved in with a friend. I even thought of going into a shelter. But we got Section 8 housing assistance just this year. We found a nice place with a kind landlord who was willing to take us in.”

Optimistic Outlook

Reflecting on her situation, Shanica says, “I feel good in spite of everything. Most Moms would be pulling their hair out by the handful but I have played the cards I was dealt as best I could. My older son, who lives with a relative, doesn’t have CF and for this I am grateful.”

But, believe it or not, Shanica is still fighting Messiah’s father over custody. “I fight right back,” she said. “He never gives up but I don’t give in.”

Shanica says her relationship with NJSOCF has been an enormous source of comfort and support. “I started with NJSOCF when I heard about their program and needed help with getting diapers. I got what I needed and have turned to them for other assistance. Debbie Sikkema always finds a way to help in any way she can. The organization is a lifesaver to us.”

Shanica’s next hope is to save enough money to buy a small used car. “Right now I am studying to pass the written driver’s license test and hope I can first time around.” she said. “I want to keep Messiah off the buses as much as possible to keep him from getting sick. I am hopeful and determined to play my cards the best way I can – for both of us.”



Joseph Tomasso continued from Page 3

Visit Joe’s website www.joesvidtodvd.com

Joe is determined to forge a career in film editing and videography to put his degree to use.

“I now have a home-based business doing editing of “old school” analogue films and videos to edit and update to DVD. A lot of people tell me I should do it full-time. I do get assignments for special events like weddings and other occasions.”

At this point in his life, Joe is content with remaining at home with his loving family and taking things one step at a time.

“I realize I am lucky to be alive and have a second shot at life,” he said. “I am trying to utilize my talents to make the best of my abilities and create things people will enjoy. I am doing it all, not only for myself, but for my family. I fought as hard as I could to push through all of my physical challenges and stay alive because I knew it would break their hearts if I didn’t. I am here for them and because of them.”

New Jersey State Organization of Cystic Fibrosis

Board of Directors

Alan M. Barone, President
Martin S. Rittenberg, Vice-President
Philip V. Luppino, Secretary
Joseph T. Miick, Treasurer
Debra DuHaime
David J. Kalb
John J. Lee
George McDermott
Debra Sikkema, Executive Director

137 Union Boulevard
Totowa, NJ 07512
P.O. Box 3648
Wayne, NJ 07474-3548
(973) 595-1232
njsocf.org

Our Mission is...

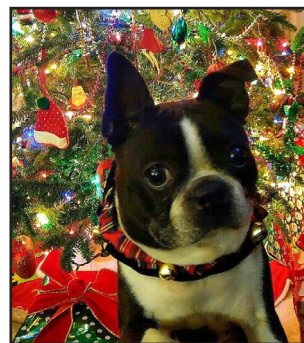
To help ease the heavy financial burden placed on CF patients and their families and to provide needed information. No other cystic fibrosis organization in New Jersey offers the same type of focused financial assistance and emotional support.

Our Motto is...

We help them breathe easier!

How to Donate

On-Line
Memorial Gifts
Matching Gifts
United Way



Mickey, NJSOCF Mascot



Volume 24, Number 2

Fall 2017

NJSOCF Celebrates 40 Years!

MESSIAH AND SHANICA DYER: The Power of Love

Shanica Dyer, 30, is a young woman who has faced more than her share of adversity but has come shining through it all with a positive attitude and approach to life that is truly remarkable.

Shanica’s son, Messiah, was diagnosed with CF a week after his birth. On hearing the news, his estranged father immediately filed for full custody of the infant even though he had never seen him. Why? “It’s simple,” Shanica says sadly, “he has always seen him as a paycheck. But I refused to let that happen.”

Messiah suffered serious pulmonary problems from the beginning and was very slow to grow. “Sometimes he would stop eating, no matter what I did and weighed only 35 pounds for a long time as a toddler,” Shanica says.

Frightened by his low weight, Shanica sought help at St. Joseph’s Hospital in Paterson. “The doctor who treated him is excellent and he is now doing well with his weight.” Shanica said. But there were other problems as well.

Messiah has been diagnosed with autism and attention deficit disorder, and Shanica is sometimes caught up in a whirlwind of emotions – his and hers.

“He can get very difficult and I have to just follow his lead,” she says. “There is no point to fighting.”

Special schools a big help

Messiah is now enrolled in an early childhood development program that has been a big help dealing with his multiple problems. “He is now nearing five years old and is on an extended school year that runs over the summer. I work in the fast food industry so we have that income along with food stamps.”

Despite all of his challenges, Shanica says Messiah is “a very happy child in general and just loves going to school. He just got a very good 30-day review.”

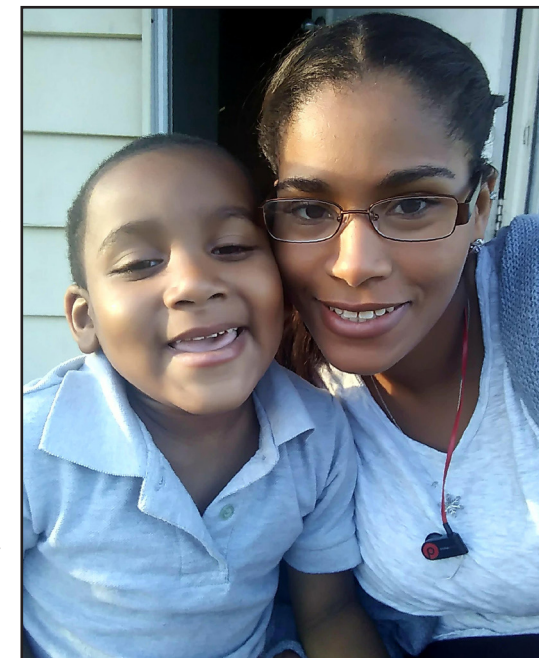
In addition to his CF regimen, Messiah takes drugs for his autism and ADHD.

“He is a fighter,” says his Mom. “He tends to be very active, which can wear me out but I love him so much I just do the best I can.”

Shanica recently enrolled Messiah in the K-Forward School which has special classes that address his problems. “Bergen County is known for their good public education and their Individual Educational Plan, which they are honoring with Messiah.”

Shanica says Messiah has had early intervention starting at the age of two and she credits his progress to getting on track for his special needs very early on.

But there have been plenty of other bumps along the way.



NJSOCF Celebrates Forty Years!

Shut your eyes and take a deep breath because it's time to blow out 40 candles on the New Jersey State Organization of Cystic Fibrosis' Birthday Cake!

It's hard to believe that four decades have gone by since founder Estelle Sikkema came up with the idea of starting a new type of organization to help cystic fibrosis patients—one that would provide direct financial assistance from birth through adulthood and also supply much needed emotional support.

Since the vision became a reality in 1977, NJSOCF has helped hundreds of people with CF in New Jersey from every corner of the state and demand never slows.

So, Happy Birthday NJSOCF – the people you serve every day of the year salute and thank you.

Special Events *34th Annual Golf Tournament*

This past August 4th golfers gathered for the 34th Annual NJSOCF Golf Tournament at Crystal Springs Country Club. The day of golf included a BBQ lunch, 18 holes at Wild Turkey Golf Course and an Awards Dinner at Crystal Springs Rotunda. NJSOCF's biggest fundraiser of the year was another huge success. We thank all those who support this important event year after year!



Bowl for CF Awareness

The annual Bowl for CF Awareness fundraiser was held on Saturday, November 11, 2017, at the New North Arlington Bowl in North Arlington. NJSOCF board member, George McDermott, once again chaired the event, raising funds and bringing awareness about cystic fibrosis to the community.

George with Angelique Sodano and daughters Cheyenne and Brianna

"POCKETBOOK BINGO"

Over 250 people filled the Pompton Lakes Elks Lodge to play Bingo for CF. NJSOCF's second *Pocketbook Bingo* was another huge success and a great time was had by all!



Coming in 2018

35th Annual Golf Tournament

SAVE THE DATE!! Come join us on **Friday, August 3, 2018** at Wild Turkey Golf Club and Crystal Springs Country Club. Old friends, beautiful courses and scenic views—Crystal Springs never disappoints. So plan to support our 35th Annual Golf Tournament and be a part of this wonderful tradition.

Visit our website for more information on Special Events

www.njsocf.org

Joseph Tomasso: Hitting his stride after a long struggle

"I have the most loving and supportive family you can possibly imagine," says 33 year-old Joseph Tomasso of Cranford. "Without their love and support I couldn't have made it."

Today, after struggling with the disease since he was diagnosed the day after birth, Joe has had a successful double lung transplant, earned a college degree and is now focusing his energies on oil portraiture, film editing and videography.

After a short time living in New York City with his former fiancé and now close friend, he is living happily back home with his family.

Early Struggles

Joe said he struggled through his childhood into adulthood, following the prescribed CF regimens but never feeling well. "I kept the fact that I had CF as quiet as possible, never telling anyone I had it until my teen years. The digestive symptoms were always worse than my pulmonary symptoms until I hit my teens, which required me to be hospitalized from intermittent pneumonias, and then at home on IV's. I had regular CF 'tune ups' every couple years."

Joe earned his AA degree at a local community college and worked at a series of retail and service industry jobs afterwards, but his condition was worsening. While also battling exhaustion and depression, he would end up being let go by his employer. "The longest I lasted at any job was one year," he said. Joe had a five-year relationship that was heading for marriage but the couple decided to break off the engagement. "But we continue to be best friends until this very day," he said.

Joe went on SSI disability because of his inability to keep a job, but managed to get his Bachelor's degree in media and film at Kean University in 2011. One of his first projects prior to getting the degree was to interview Debbie DuHaime, a NJSOCF Board Member, about her work in the broadcast industry. "We have become great friends over the years and my family has also become close to her," he said.

"I had been on the NJSOCF Adult Program for a number of years and just hit it off with Debbie," he said. "We are very close and share a strong religious faith and believe deeply in the power of God."

However, by 2014 his condition took a dramatic turn for the worse. "This was the worst time of my life," he said. "My doctor, Emily DiMango of Columbia Presbyterian's famous pulmonary department, told me I needed a double lung transplant immediately and referred me to Duke University because she said I would be higher on the waiting list," Joe and his parents temporarily moved to North Carolina and after several weeks of grueling pulmonary rehab—during which he required up to 20 liters of oxygen—he had a successful transplant in January of 2015.

Throughout it all his family, along with close friend Debbie DuHaime, provided Joe with all the love, prayer and encouragement he needed.

Finding a new focus

Fine art has always been something that had been of interest to Joe and he took some painting classes at Kean. "After one course, I realized I had some talent and decided to get serious about it. I do mostly portraits and still life subjects and recently completed a portrait of the Madonna for my sister."

