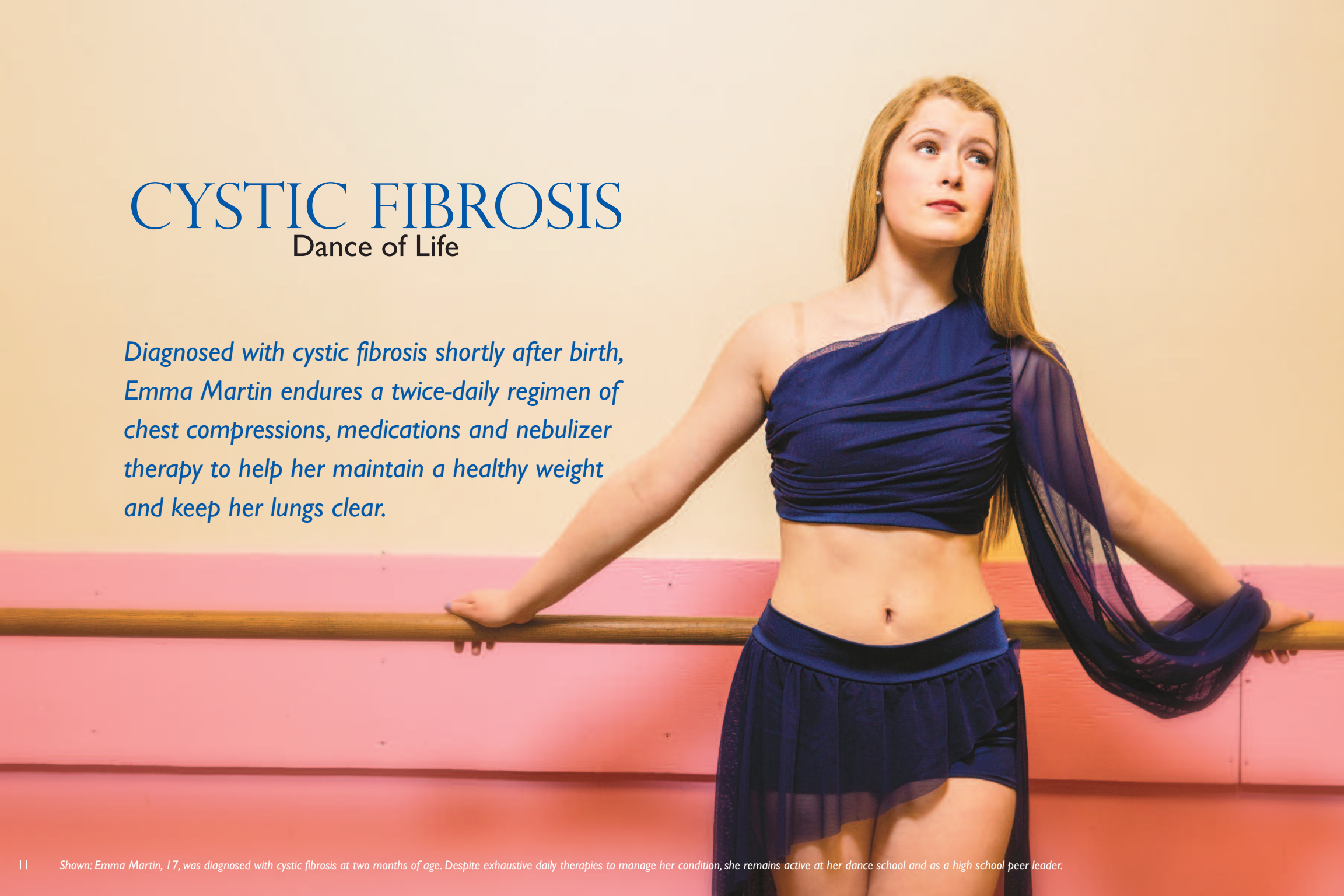
# CYSTIC FIBROSIS

## Dance of Life

*Diagnosed with cystic fibrosis shortly after birth, Emma Martin endures a twice-daily regimen of chest compressions, medications and nebulizer therapy to help her maintain a healthy weight and keep her lungs clear.*





*Shown: Emma Martin, 17, was diagnosed with cystic fibrosis at two months of age. Despite exhaustive daily therapies to manage her condition, she remains active at her dance school and as a high school peer leader.*

There are no breaks or vacations from cystic fibrosis (CF). The exhaustive, daily therapy is a constant reminder of the chronic condition, but don't expect Emma to complain about it. "Living with cystic fibrosis has made me stronger," Emma explained. "I wouldn't be the person that I am now without having to live with it for my entire life."

According to the Cystic Fibrosis Foundation, CF is a life-threatening genetic disease that causes mucus to build up and clog some of the organs in the body, including the lungs and pancreas. When mucus clogs the lungs, it can make breathing difficult. The thick mucus also causes bacteria (or germs) to get stuck in the airways, which causes inflammation (or swelling) and infections that lead to lung damage.

Mucus also can block the digestive tract and pancreas, preventing digestive enzymes from getting to the intestines. The body needs these enzymes to break down food, which supplies nutrients people need to grow and stay healthy. Individuals with cystic fibrosis often need to replace these enzymes with medicine they must take with meals and snacks.

"Any small respiratory infection can be a threat to someone with Cystic Fibrosis," said Thomas Scanlin, MD, Professor of Pediatrics, Chief of the Division of Pulmonary Medicine and Director of the Cystic Fibrosis Center at Rutgers Robert Wood Johnson Medical School and Robert Wood Johnson University Hospital. "A cold for most people can become pneumonia or bronchitis for someone with cystic fibrosis."

That's why, he notes, it's important for patients and family members to be "active participants" in managing the disease.

Emma's CF has already led to periodic hospitalizations due to lung inflammations and infections. And maintaining a healthy weight has also been a challenge. But because she is committed to managing her condition, she has been able to maintain an active lifestyle.

A Metuchen resident and junior at Bishop Ahr High School in Edison, Emma is a member of the National Honor Society and the Spanish Honor Society. She is also a Peer Leader, mentoring incoming first-year students.

Emma also dances four days each week at Ms. Doreen's Fabulous Feet Dance Studio in Metuchen. She performs a broad range of dance styles including ballet, point, tap, jazz and lyrical. Her school participates in regional and national competitions and Emma remains a key part of the team because she is determined to manage her CF.

"It's always 365 days a year, you have be committed to your medical treatment," Emma's mother Carol notes. "Emma takes charge of doing everything she needs to do."

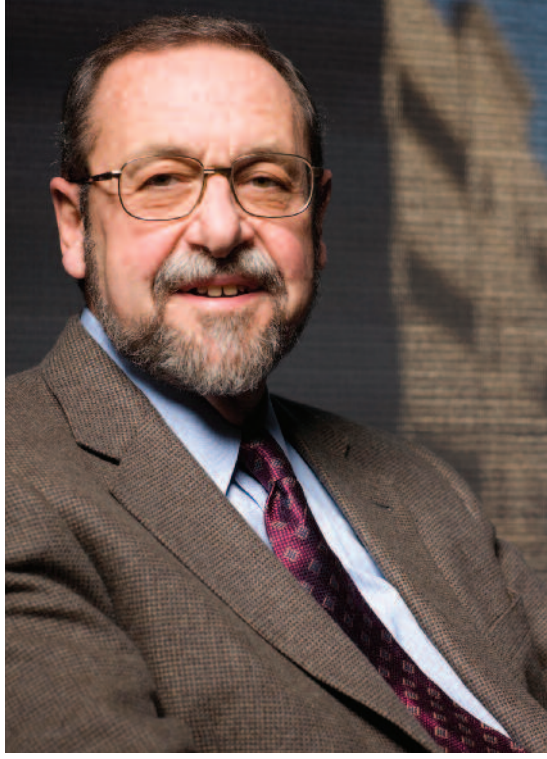
Mrs. Martin also credits the Cystic Fibrosis Center with helping Emma stay on track. The CF Center features a multidisciplinary team that includes physicians specializing in CF and pulmonary medicine, nurse practitioners, respiratory therapists, social workers, registered dietitians and psycho-social support. It is ranked among the top five centers in the nation for maintaining its patients lung function and nutrition status.

"The relationship we have with the child becomes as important as the relationship we have with the parents," noted Erin McElroy-Barker, LCSW, a Social Worker and CF Center Coordinator. "Because this is a lifelong illness, the family has to be part of the care team."

Until recently, the long-term prognosis for CF patients wasn't positive. However, new breakthroughs in research provide hope. Emma, for example, has benefitted greatly from a new drug, Kalydeco. While only four percent of CF patients respond to Kalydeco, it has helped her breathe easier, digest food better and maintain a healthy weight. The CF Center also participates in clinical trials to test other new medicines that provide hope.

"I'm grateful for the support from my family, friends and my second family at the dance studio," Emma explained. "CF is a big part of who you are, but it's not the only part. You make time for the things you love to do."

Visit www.bmsch.org/cf or call 1-888-MD-RWJUH.



*According to Thomas Scanlin, MD, Professor of Pediatrics, Chief of the Division of Pulmonary Medicine and Director of the Cystic Fibrosis Center at Robert Wood Johnson University Hospital and Rutgers Robert Wood Johnson Medical School, (shown above), CF patients and their families must be "active participants" in their care.*