



Meet Stanley Zolek, a nine-year-old Holmdel resident who is determined to make CF (Cystic Fibrosis) stand for CURE FOUND!

STANLEY & CYSTIC FIBROSIS

What You Need to Know About Both of Them

STORY SUSAN MURPHY

Stanley Zolek lives in Holmdel with his parents, seven-year-old sister Skylar-Rose, and three-year-old brother Sebastian. Stanley and Skylar enjoy riding their dirt bikes together and Stanley and Sebastian play cars, video games, and climb trees together. Just like many nine-year-olds Stanley loves playing with his Legos, army men and hanging with what he labels "his totally awesome family."

This young boy with the positive attitude, a ready smile, and an appearance of healthiness is not like other nine-year-olds. Stanley has Cystic Fibrosis (CF), a genetic disease affecting approximately 30,000 children and young adults in the United States. A defective gene causes his body to produce an abnormally thick, sticky mucus that clogs his lungs and leads to life-threatening lung infections. These thick secretions also obstruct the pancreas, preventing digestive enzymes from reaching the intestines to help break down and absorb food. The mucus also can block the bile duct in the liver, eventually causing permanent liver damage. CF is a deceiving disease; so while Stanley looks healthy on the outside, inside his body there is a lot going on.

Although Stanley's parents, Dawn and Stan Zolek, knew they were both carriers of the defective CF gene when Dawn was pregnant, Stanley wasn't diagnosed until he was two-weeks-old. "My husband and I were of course devastated when we heard the news that Stanley had CF, however we decided to take a pro-active approach from the beginning and really try to make something out of this card we were dealt. Our family immediately became involved with the Cystic Fibrosis Foundation, we networked with families who were also affected by this disease and launched an 'awareness campaign' through Stanley's personal website www.ilovesstanleynyc.com."

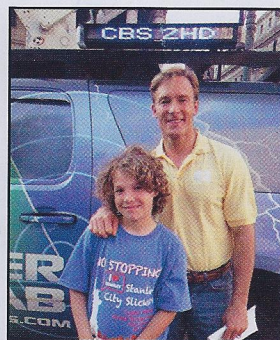
Each year, the NYC Great Strides Walk for Cystic Fibrosis is held to raise funds and awareness. The Zoleks attended their first walk in 2005 when Stanley, just 9-months-old, was asked to cut his first ribbon. At that time, the walk was held in uptown New York City with a little over 100 participants, and \$125k was raised in donations. In 2006, the Zoleks moved the walk to Battery Park City where they had originally lived, and chaired the event for the next five years. "Our family knew there was a sense of community and strength in downtown after experiencing 9/11. We saw more opportunity to connect to the community and bring the awareness to the disease that was needed," explained Mrs. Zolek. Within three years, the walk grew to include over 1,000 people. Today, Stanley is still the poster child cutting the ribbon and the Zoleks work very closely with the Foundation, families and the community as the "Family Ambassador."



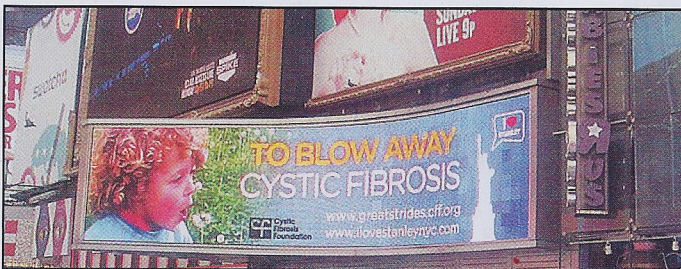
The strong team of "Stanley's City Slickers" attend NYC Great Strides CF Walk.



Left to right: Skylar-Rose, Sebastian, and Stanley Zolek are siblings and friends.



Stanley Zolek and good friend and supporter Boomer Esiaison of CBS.



When Stanley Zolek was younger, he was featured on a Times Square billboard stating his wish was to blow away Cystic Fibrosis.

This year, the walk took place on June 2 and was very successful. Although the CF Great Strides walk is over, donations are always welcomed. According to the information on Stanley's website, all donations will be credited to Stanley's City Slickers and will be used effectively and efficiently for CF. More than 96 cents out of every dollar contributed is used to fund the vital programs of the CF Foundation.

Year after year, committed and passionate family members and friends have helped the Zoleks with the CF awareness campaign and NYC Great Strides weekend. "Our strong team of 'Stanley's City Slickers' has raised over \$500k for CF and are determined to continue making 'great strides' for CF. Stanley's health attributes a lot to the family and friend support we receive and we are so thankful. It takes a village to push through this and we are so fortunate to have a strong network," said Mrs. Zolek.

Stanley's daily routine is challenging and takes patience, time management due to the at-home treatments he needs, and lots of love and support from his family. Stanley needs to be very careful with germs and exposing himself to environments that can harm him. Since his body produces an abundance of mucus, germs stick to his lungs thus having a damaging irreversible effect on his lungs. Mrs. Zolek shared that every day, Stanley performs therapy on an airway clearance vest and inhales heavy antibiotics on his nebulizer three times a day. Since his pancreas is also affected, he needs to take over two dozen pills a day to help digest his food. Without these pancreatic enzymes he would not be able to absorb and digest his food. "Managing CF takes up a lot of time, which is challenging for an active nine-year-old."

Mrs. Zolek emphasized, "It is important for the public to know that CF does not receive any federal funding. The Founda-

tion solely relies on our support to generate the awareness and funds needed to combat this disease. Due to this support, there have been huge advancements with research. In the 50's, CF kids weren't expected to live through elementary school. Today, because of your support, many people with the disease are living into their 30's and beyond. The disease is also much more manageable today. A lot of the therapies which were originally required to be done in hospitals, are now being handled in the home." The research and care supported by the Foundation has made a huge difference in extending the quality of life for those with CF. Over the past few years, the life expectancy for this disease has fortunately increased to the mid 30's.

"Over the past nine years, Stanley has struggled with this disease, however he handles CF in an optimistic way. Through his Public Service Announcements with CBS and Boomer Esiason, his billboards in Times Square and street marketing wild posting campaigns, Stanley is determined to make CF stand for CURE FOUND. His website has been the source of inspiration for many. Just recently a young man with CF from Thailand reached out to Stanley through his website. The connections being made are worldwide," said Mrs. Zolek.

Stan and Dawn Zolek offer this final thought about CF and their nine-year-old son Stanley, as well as the 30,000 other children and young adults. "With Cystic Fibrosis, your healthiest day was yesterday. But with Stanley, his happiest day is today."

Further information about the Cystic Fibrosis Foundation can be found at www.cff.org or by calling (800) FIGHT CF. Visit www.ilovestanleynyc.com to learn more about this optimistic and determined nine-year-old Stanley Zolek.