

In the playground of Rockefeller Park in Battery Park City, two-and-a-half-year-old Stanley Zolek could not be having more fun. He is in constant motion, running, jumping and climbing, his rosy, cherubic cheeks growing redder, his long, curly locks bobbing with every move.

All the while, Dawn and Stan Zolek's eyes never leave their child.

"When he's running around like this it's more stressful to me," says Dawn, her newborn, Skylar-Rose, bundled in a carrier at her chest.

It is not the fear of a bone-breaking fall or some miscreant stranger that haunts the Zoleks. It is infection.

Born with cystic fibrosis, or "CF," a progressive disease of the lungs and pancreas, Stanley can't afford to get the colds and coughs that other children routinely pick up, and most parents take in stride.

"I have to make sure that he keeps his hands out of his mouth, and he's not around a kid who's coughing," says Dawn, 33. In her hand, an antibacterial wipe is clutched and ready for action.

"There are so many germs around in the sand, you gotta watch out," adds Stan, 35. "This is germ heaven, baby."

The Zoleks, who live in Battery Park City's Gateway Plaza, say they owe Stanley's beefy build and robust energy to their scrupulous control of his world—his playmates, hygiene, environment, nutrition and twice-daily therapy regimen that most CF patients require.

The disease causes an overproduction of mucus that can act as a host for dangerous bacteria. As Stan puts it, "The mucus is like a tar driveway in summer. The tar softens and whatever falls on it sticks on it."

Bacterial infections in the lungs can mean hospitalization, irreversible scarring and, down the road, lung disease that only a transplant can cure.

"To keep him healthy these first few years is vital," says Dawn.

Each morning and afternoon, Stanley sits through a 45-minute treatment. Breathing

through a mask, he inhales a medication that helps to open his air passages. A newly acquired vibrating vest loosens the mucus, and then he gets a gentle pounding to further clear his lungs. Every couple of months Stanley gets a cold, and a third treatment is added to the day, along with a saline mist, antibiotics and steroids.

Stanley rebelled against the vest at first, but now tapes of "Bob the Builder" and "Little Bear" are all he usually needs to sit still for the lengthy treatments. "It's a way of life," says his dad.

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# STANLEY'S WORLD

**For this Battery Park City family, caring for a child with cystic fibrosis is a way of life, and a way of love.**



Dawn Zolek, with Skylar, chases Stanley in the playground at Rockefeller Park.



Twice a day, and more often if he is getting a cold, Stanley inhales albuterol, a medication that opens his air passages and makes breathing easier. During the treatment, a vibrating vest helps to loosen mucus.

STORY AND PHOTOS BY  
CARL GLASSMAN



Top: Stanley eats his breakfast and, as with all meals and snacks, it includes apple sauce with added enzymes. The pancreas of CF patients doesn't function normally, requiring the digestive aid. Above left: To convince Stanley to wear his new vibrating vest, Stan, his father, makes it look like fun. Above right: Dawn helps her son with his breathing therapy. Below: Stanley climbs in Rockefeller Park.



### STANLEY'S WORLD

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Because Stanley's pancreas does not produce the enzymes needed to digest his food, digestive enzymes are added to applesauce and given to Stanley with every meal and snack.

Ever vigilant, the Zoleks frequently scrub the apartment, wash their hands, and open doors with elbows or paper towels. If Stanley attends a playgroup or toddler music class, Dawn makes sure it's in the early morning, before bacteria has a chance to build up in the room. It's not unusual for her and Stan to cancel social plans because someone in the group has a cold.

They don't know yet if they will risk putting Stanley in preschool this fall. They're eager for him to socialize with other children, but fear the infections that can come with it.

"I only want to put him in school in September and October, then take him out during flu season," Dawn says. "If I have to pay I have to pay. I'll do what I have to do."

Twenty years ago, children like Stanley were not expected to live beyond their teens. Today, the life expectancy is almost 40, the result of new antibiotics, anti-inflammatory drugs and better nutrition.

This month, Stanley's family and hundreds of others will be doing their part to continue the progress against the disease. For the second time, Stanley is the poster child for the "Great Strides" walk, which benefits the Cystic Fibrosis Foundation and takes place this year on May 13 in Battery Park City. (See box on opposite page.)

Dawn and Stan co-chair the event. Last year the Zolek team of family and friends—"Stanley's City Slickers"—raised more than \$30,000 for the foundation, which has been at the forefront of

cystic fibrosis research and patient support for 50 years.

To help personalize the disease the Zoleks have created a Web site, [www.ilovestanleynyc.com](http://www.ilovestanleynyc.com). In a series of photographs, they show their baby son growing like any healthy child, in spite of his disease. Because CF is much less common than cancer and some other serious diseases—it afflicts 30,000 Americans—the Zoleks are trying to educate the public and raise awareness.

"Most support comes from family and friends of CF patients," Dawn says. "Corporations don't want to support something that doesn't affect a lot of people."

The Zoleks knew little about the ailment until Dawn was pregnant and the couple discovered, through genetic testing, that both carried the gene—a factor required for a child to be born with CF. There was a one-in-four chance that the fetus had the disease, and an amniocentesis would have told the story. Dawn and Stan chose not to know.

"We weren't going to abort the baby," says Stan.

The Zoleks took no chances with



their second child. They underwent a process called pre-implantation genetic diagnosis. Following in vitro fertilization of eggs, a specialist in Michigan tested five of them and found that one would develop into a baby with CF, two were only carriers of the gene, one was neither and one couldn't be determined. The strongest candidate for surviving to birth, a carrier, was selected.

In February, Skylar-Rose was born. Juggling duties with a CF child and a newborn is a challenge, says Dawn, who is on leave from her job as an event planner for MTV. But somehow she makes it look easy.

As she holds Stanley on her lap for his twice-daily treatments, the baby lies with-

in reach on the couch behind them. If Skylar starts to fuss a little, Dawn comforts her in one arm while holding Stanley, and continuing to give him therapy, in the other.

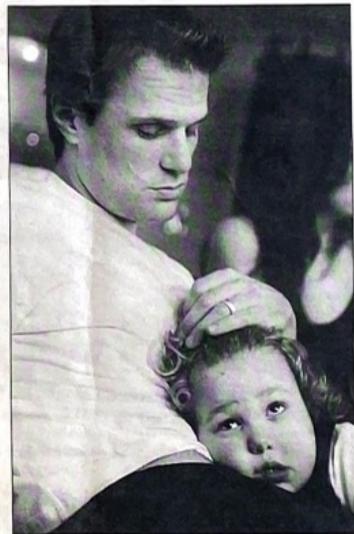
"Having a second child in our situation is a necessity, not a burden," says Dawn. "It helps ease our minds knowing that they will always be there for one another in time of need."

Knowing that Stanley's life will likely not span as many years as those of healthier children is a "daily thought," says Dawn.

"But that doesn't change anything," she adds, "because we believe that life isn't measured by the amount of time. It is measured by what you put into that time."

### You can join Stanley's team in the fight against cystic fibrosis

On Saturday, May 13, Stanley and his family and friends will join hundreds of others in the three-mile "Great Strides" walk, benefiting the Cystic Fibrosis Foundation, in Battery Park City. The fundraiser begins at 9:30 a.m. in Battery Park and includes breakfast, lunch, music and raffles. To walk with Stanley, or just make a donation, go to [www.ilovestanleynyc.com](http://www.ilovestanleynyc.com).



Above: While checking on her newborn, Skylar, Dawn gently pummels Stanley's chest to help loosen mucus. She says she worries that she can't give the baby all the attention she would like, but adds, "These first few years in Stanley's life are very important."

Left: Stan, an oil funds manager at the Mercantile Exchange, relaxes with his son following an afternoon treatment. "You try to take life as good as you can, and just day by day" says Stan. "That's all you can ask."