



TAKING STEPS TO CURE CYSTIC FIBROSIS

# Taking Strides for Ella



A Pulmonary Function Test helps determine Ella's lung health.



Ella spends two hours a day doing breathing treatments to keep her lungs clear.



In order to stay healthy, Ella has an arsenal of antibiotics, enzymes, vitamins, nasal sprays, inhalers and nebulized medications.



Ella has frequent blood draws to monitor her vitamin levels.



This past year Ella had two surgeries to remove nasal polyps and unclog her sinuses.

## Portland Great Strides Walk

When: Saturday, May 21<sup>st</sup>

Time: 9:00 Check-In  
10:00 Walk Starts

Where: Oaks Amusement Park

### Great Strides at a Glance

- Signature event for the Cystic Fibrosis Foundation over the past two decades.
- Raised nearly \$35 Million last year through 12,000 Team Leaders and 250,000 Supporters.
- Over 600 walks held throughout the country.

### Why Support the Cystic Fibrosis Foundation

- The Foundation's "venture philanthropy" business model has yielded a pipeline of more than 30 promising CF therapies.
- The CF Foundation is one of the most efficient organizations of its kind with \$.90 of every dollar raised going to support research and programs.
- Thanks to wise investments by the Foundation in CF research and care, the median predicted age of survival for people with Cystic Fibrosis is now more than 37 years.

<http://greatstrides.cff.org>

# Ella's Story

Ella seems like any other seven-year-old girl. She loves dressing up, playing pretend, singing and dancing. She recently found she has a talent and love for gymnastics and this year, she magically became a great little reader. With her sweet smile, infectious giggle and quick wit, she lights up any room. When asked what she wants to be when she grows up, Ella enthusiastically says, "A mom!" but then adds, "a dancer, a teacher, and a doctor" to her ever-growing list. From the outside, Ella appears to be a normal little girl, but every day, inside her body, a battle is being waged. You see, Ella has Cystic Fibrosis.

Cystic Fibrosis is a life-shortening genetic disease that affects the respiratory and digestive systems of 30,000 Americans.

Ella appears to be a normal little girl, but over the past seven years she has made more trips to the doctor than you can count and has had numerous blood draws, throat cultures, x-rays and breathing tests. She faithfully does a number of treatments to maintain her health and stay one step ahead of this progressive, degenerative disease. Ella spends over an hour every day hooked up to a special vest and compressor system that vibrates her chest to ensure mucus is not building up in her lungs and she does breathing treatments with a nebulizer to battle the thick sticky mucus and chronic lung inflammation that characterizes Cystic Fibrosis.

Smart, funny and wise beyond her years, Ella faces her Cystic Fibrosis head-on, every day, with a positive attitude, and a sense of determination and maturity to marvel at. She just takes it all in stride. An amazing feat, on one hand, but also so heart breaking, to know this is what she has come to expect from her life. She knows chances are good she will end up in the hospital at some point – something inevitable for those with Cystic Fibrosis, and she is beginning to see, in those CF friends she has, the terrible ways Cystic Fibrosis can manifest itself. Right now the median life expectancy for those with Cystic Fibrosis is 37 years, but we are still losing precious lives way too young – six-year-olds, ten-year-olds, thirteen-year-olds.... They're dying every day.

Cystic Fibrosis causes the body to produce a thick, sticky mucus which, in turn causes infection and inflammation.

More than 10 million Americans ~ 1 in every 30 ~ are symptomless carriers of the defective gene that causes Cystic Fibrosis.

Recently, Ella has learned some especially heart-breaking things.

She has become keenly aware of how different she is from her friends. She has learned needles really do hurt just as much every time and no one really ever gets used to throat cultures. She understands she must show a maturity well beyond her years and that, unfortunately, she will continue to be asked to do things no child should ever have to do. She knows Cystic Fibrosis can make you very, very sick, no matter how hard you work to stay healthy. But, above all that, Ella has truly come to believe there will be a cure for Cystic Fibrosis.

**She can only hope you will choose to be one of those working with her to make that belief a reality.**

