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Ridgewood girl's wish comes true

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When discussing her hobbies, 8-year-old Chloe Fernandez appears no different from any other girl her age, but she has already accomplished more than some people do in a lifetime.

With the help of Make-A-Wish and the Macy's Believe Campaign this holiday season, she is a published author who just had her first book preview.

The precocious 8-year-old loves being active. She plays dress-up and often pretends to be Rowan Blanchard from Disney Channel's "Girl Meets World," putting on a show in the living room for her dolls. She rides her scooter around the house, even though it "drives Mom crazy," she said. She also swims and plays the piano and harmonica.

But when Chloe swims, she can only go to the pools at HackensackUMC Fitness & Wellness Center in Maywood because they contain filtered salt water as opposed to chlorine. And Chloe attends harmonica lessons at Holy Name Hospital in Teaneck; she took up the activity because it's been proven to help lung function.

Suddenly, the normal 8-year-old image is skewed. Chloe is afflicted with a rare genetic condition called primary ciliary dyskinesia (PCD), a disease that attacks the cilia or "the natural hairlike extensions on the mucus membrane that help us clear our secretions," according to Dr. Donna Lee, Chloe's pulmonologist at Joseph M. Sanzari Children's Hospital at HackensackUMC.

"Patients with PCD are born with defective cilia," said Lee. "So, they cannot clear their own secretions. That will lead to repeated ear infections, sinus infections and lower respiratory tract infections."

In other words, having cilia defects can make sneezing or coughing out mucus difficult. An excess of mucus is thus created, bogging the lungs. Breathing is compromised and a high exposure to viruses and bacteria develops.

A cure for PCD is currently non-existent. Chloe relies on her lung therapeutic activities, and medicinal treatments such as a nebulizer and a vest airway clearance system. Her mother, Leslie Mota, supplies Chloe with the vest three times a day, and four to five times if her daughter is sick - and she frequently is.

"At five months [old], she had RSV (respiratory syncytial virus) twice," said Mota. "I thought it's one of these things that happen when babies are in day care. But she just progressively got a little



MARION BROWN/STAFF PHOTOGRAPHER

Chloe Fernandez, 8, recently signed preview cards of her book "PCD Has Nothing on Me," as part of the Make-A-Wish and the Macy's Believe Campaign. Above, Chloe signs autographs for her uncles Mathew (left) and Justin Rosario of Glen Rock. They are two of her biggest fans.

worse."

By the time Chloe was 1, she was declared chronic asthmatic; however, she wasn't responding to regular asthmatic treatments. Chloe was in first grade at Somerville Elementary School when she contracted pneumonia and bronchitis more than seven times.

Mota pulled her out of school, and Chloe was sent to Children's Hospital of Philadelphia and Hackensack Hospital for more testing. A proper diagnosis was finally determined through a lung biopsy.

But adjusting to a different lifestyle than her friends was initially hard to take for the third-grader, who learned she'd have to be home-schooled for the majority of a school year.

"She was a little upset and depressed, quite frankly, over not being normal," said Mota. "She said, 'I just want to be normal.' And I said to her, 'Everyone has their own normal and this is our normal.'"

Chloe adhered to her mother's words. Mota gave her notebooks so she could write, an outlet to express what she was thinking and feeling.

"At first it was kind of hard to jot down what I thought," said Chloe, "because it wasn't just my hand writing out words that I thought were in my head. I had to think for a while."

Her trips to the hospital helped break through her writer's block. Chloe enjoys interacting with other sick kids, and by doing so, she discovered that all kids with chronic illnesses have similar experiences.

"It's scary, it's lonely, it's frightening, it's boring at times," said Mota. "She said, 'Mommy, you're right. We all feel the same way.'"

Chloe managed to compile three notebooks replete with information on her condition and how she lives with it. She even wrote in chapters and came up with a book title, a mission to publish her journals in mind. Mota was all in.

"Chloe realized there's not a book that we can really like," said Mota. "Is there a sick kid that talks to us?"

Mota contacted the New Jersey chapter of the Make-A-Wish Foundation, which was more than happy to grant Chloe's wish. The organization set her up with an editor and illustrator who were skeptical that an 8-year-old wrote such a book, until they met the mature little author.

The book, "PCD Has Nothing on Me," is informative but "funny," said Chloe.

"I decided to write the book for the kids. I wanted to let them know that they're not alone, and that there are other kids who have PCD," she said, adding that adults can read the book, too.

She believes it captures her challenge for kids to "find who we are, and that we could do anything we want to do," a reflection of how she has chosen to lead her life.

Macy's Believe Campaign got wind of Chloe's story when it was in the process of selecting a Make-A-Wish kid whose wish was being granted. For every letter written to Santa, Macy's is donating \$1 to the foundation up to \$1 million. Macy's chose to showcase Chloe and her book for its annual National Believe Day at Westfield Garden State Plaza earlier this month.

A couple hundred people turned out for the event, which included a DJ and a question-and-answer session for Chloe. Make-A-Wish and Macy's had postcard handouts of Chloe's book cover, enabling her to practice signing her autograph: "Chloe R. With hope and love."

She'll get more practice signing autographs when her book signing at a Barnes and Noble store takes place next month (date and location still to be determined), yet another gift from Make-A-Wish. "PCD Has Nothing on Me" will then be available at Barnes and Noble and Amazon.

"[Make-A-Wish] goes beyond what even a wish is," said Mota. "We're beyond humble and grateful that [the organization] wanted to capture Chloe's story and give her that voice."

"It was like Disneyland," added Chloe with a smile.

Chloe, who is described as "attentive, enthusiastic and focused" by her home-school teacher Cynthia Sickles, doesn't want to stop at one book. She'd like to write more, and wants to start her own PCD foundation one day and call it "My Life, Our Hope Foundation." Her humanitarianism always carries through, even during holidays and her birthday. This Christmas and her birthday (Jan. 9), she has selflessly asked family members to donate to the PCD Foundation in lieu of gifts. Her family, including her big brother Nick Mota, admires her endless efforts to give back.

She's restless with excitement that Macy's and Make-A-Wish have made her dreams to spread awareness come true, but she's

hoping one person in particular can, too.

"Ellen [DeGeneres]," said Chloe, who likens the popular talk-show host to "a big kid."

"She said, 'Mom, everyone in the entire universe watches Ellen and they'll all know about PCD,'" said Mota. "I told her it's hard to get there, but who knows?"

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