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## 'Extraordinarily special' girl from Ridgewood published book

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RIDGEWOOD - Ridgewood resident Chloe R Fernandez was a bundle of excitement when she discovered a limo parked outside her home, ready to whisk her away to her first-ever book signing at Barnes and Noble on Route 17 South in Paramus last Saturday.

It was also the 9-year-old author's first-ever limo ride.

"It was so exciting, I couldn't breathe," she said while demonstrating how surprised she was. "I was in the limo going, 'Breathe, Chloe, breathe!'"

The special ride was yet another gift from the Make-A-Wish Foundation, which answered Chloe's request to publish a book that she wrote called "PCD Has Nothing On Me." The 47-page chapter book chronicles Chloe's life as a child afflicted with primary ciliary dyskinesia (PCD), a rare genetic condition that attacks the cilia or hairlike extensions on the mucus membrane that clear airway secretions. She wanted to put into words how her illness affects her, but also provide a voice for other kids with chronic diseases.

"It's really important for our wish children to educate others on how their life is impacted by their illness," said Stacy Kreizman, senior director of outreach and mission delivery at Make-A-Wish New Jersey. "We are really honored at Make-A-Wish that we can help with that process."

Their help allowed Chloe to be the center of attention at the bookstore. She sat poised behind a table that was set up with stacked copies of her book, along with a basket of sapphire blue Make-A-Wish handout bracelets. On the side were vanilla and chocolate cupcakes for her readers to munch on. She dazzled the steady flow of people who came for her two-hour signing, wearing a yellow, floral-printed dress, with sapphire blue flats and a glittery headband. It is Chloe's trademark to always dress fancy like this, as she tells in her book, because her mother said: "Always dress from the inside out. Let your outfits complement who you are inside."

"She purposely chose her shoes to be blue because of Make-A-Wish," shared Leslie Mota, Chloe's mother. "And then for the dress, she wanted something to represent Josephine's Garden at Hackensack Hospital."

Josephine's Garden at Joseph M. Sanzari Children's Hospital at HackensackUMC, where Chloe receives her treatment, is a magical outdoor escape for children that was donated by the family of the



MARION BROWN/STAFF PHOTOGRAPHER

Chloe Fernandez, right, a Make-a-Wish child, signs her book "PCD Has Nothing on Me" for Paulina Nunez, left, and Adriana Nunez. Chloe Fernandez, a Make-a-Wish child, at the signing of her book "PCD Has Nothing on Me" at Barnes and Noble gets a hug from her doctor, Dr. Donna Lee.



young Josephine Rispoli, who passed away from a high-grade brain tumor nearly five years ago. Chloe decided flowers on her dress would appropriately pay tribute.

"Josephine's Garden makes me feel very happy when I'm in the hospital, so I decided to represent her in my dress," said Chloe.

Chloe's pulmonologist at the hospital, Dr. Donna Lee, and her nurse, Michelle Leone, who have treated her for a number of years, were hardly surprised to hear how thoughtful she can be.

"She's just so extraordinarily special," said Leone, who, like Lee, made sure to be present at the book signing. "We see so many children – we love all our patients – but there's something very special about Chloe and just how she conducts herself and how she handles her illness. We wouldn't miss [the book signing]."

Chloe's wish was particularly "inspirational," said Leone. Mota gave her daughter notebooks to jot down her thoughts, pour out her frustrations and feelings regarding her illness. Chloe made it more than a venting outlet or hobby; she turned it into a valuable source for families with and without sick children.

"Leslie first approached me about how she read Chloe's journal and it really brought tears to her eyes," recalled Lee. "She came to me and wondered how she can get this journal published, and that's when she said I'll keep looking through Make-A-Wish. I said that would be perfect. If anybody could make it happen, it's probably Make-A-Wish."

Make-A-Wish referrals are from parents or medical professionals who identify a child who is facing a life-threatening medical condition and want a wish granted. For Kreizman and Make-A-Wish New Jersey, Chloe's wish was uncommon.

"We grant wishes in typically five categories: I wish to go, I wish to have, I wish to be, I wish to meet and I wish to give," explained Kreizman. "This is definitely something that is unique where a child who wanted to publish her own book wishes to get the information out there to others about what she lives with every day."

Her wish is multifaceted enough that it falls into almost all of the aforementioned categories.

"We were all so floored because most children want to go to Tahiti or they want to go to Disney," said Leone.

Not Chloe. She diligently autographed books with a blue sharpie, while Lee was on the sidelines expressing her relief for a patient who is not letting PCD dictate how she leads her life. Being born with defective cilia causes Chloe to have repeated ear, sinus and lower respiratory tract infections. Her breathing is frequently compromised as a result, and she becomes more at risk for viruses and bacteria, which makes staying in school for a whole year very arduous.

"So, when I took her out of school, I was more afraid that, from a developmental standpoint, that she's going to regress," said Lee. "In other words, school is not just for education, it's also for socialization. And I'm really glad that she found a different way [to be social] outside of school. She didn't wallow and she's in this defiance stage where she says, 'I'm not doing this.'"

"We cry when the kids cry when they can't go back to school for a while," added Lori Chiavelli, Chloe's respiratory therapist. "It's such a social outlet."

But Chloe, who Chiavelli described as a "charming, vibrant young lady," channeled her energy toward getting her words published instead. She teamed up with her book illustrator, Kaitlyn Cooper, who interned with Make-A-Wish last summer, to tell her story through drawings that were as realistic as possible.

"I would go along and read each chapter, and try to come up with one picture for each chapter and send it to Chloe," said Cooper. "She would tell me what she thought of them."

After working closely with Chloe for some time, Cooper felt the book is a "good representation of her" because it contains a lot of her positive attitude.

"It's bittersweet because she's obviously had issues that other kids her age haven't had to deal with, and in a way it's made it really difficult for her to lead a normal life," said Cooper. "But the story kind of shows that she is just a normal kid and she's just looking to have fun when she can in a safe way."

Like her four-page dedication in "PCD Has Nothing On Me," Chloe took a moment to thank her parents, hospital staff, close friends and family, and Make-A-Wish for helping her dreams become a reality. To the assembled crowd, she said: "Thank you so much for showing up; that really shows that you really care."

Chloe's 25-year-old brother, Nick Mota, stood proudly as he watched everything come together, while remembering "all those nights that she was stressing about writing the book and not knowing what to write" because she wanted it to be perfect.

"Not that I ever doubted what she could do, but now that she has this as a stepping stone, I don't see anything stopping her," he said.

"She doesn't look like she wants to slow down."

Her father, Ricardo Fernandez, is grateful that Chloe's "doing pretty good" and credited Leslie for thinking about the notebooks and reaching out to Make-A-Wish. Chloe is already on track to complete her second book, and preparing for future book signings.

Her mother's wise advice on how to choose her outfits shined through Chloe's dress that day, though her unwavering smile spoke to another line she wrote in her book: "But my mom tells me my best look will always be the smile on my face and being kind to others."

It was.

"It's been very, very amazing," said Chloe after signing a round of books, "and I'm smiling!"

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