Personal Profile: Delaney Barnett

"Two years ago I was always covered in bruises. I had to take blood thinners because I got blood clots all up my arm from an IV," said Delaney Barnett, pausing to let out a cough. "Sorry," she would quickly whisper after each of her coughs, periodically interrupting her own story. "I still remember one day when I walked into my Grade 10 math class and took a seat beside Matt Larmore and he turned to me and asked, 'What did you do? Get attacked by a bear or something?'" said Barnett, lowering her voice to mimic what Matt sounded like. "I just looked at him and said, 'Yes. Yes Matt, I was attacked by a bear.'"

On April 13th 1993, Barnett was born in the Ottawa Riverside Hospital a month earlier than expected. At seven months, Barnett was diagnosed with Cystic Fibrosis (CF.) The disease is one of the most common fatal genetic disorders in Canada.

Being premature, the doctors kept a close watch on her health. By the time she was seven months old they started noticing that instead of her growing bigger, she was getting smaller.

"My doctor knew that people who have the disease tend to sweat a lot so she bent down and kissed my forehead to taste how salty I was from perspiration," said Barnett. "After the doctor kissed me she looked up at my parents and told them I probably had Cystic Fibrosis."

Barnett was sitting in one of the blue couches of her small living room petting her beagle with her feet that lay on the ground below her. A bunch of freckles spot her nose and under her eyes

and her brown hair hung messily past her shoulders covering part of the tiger's face printed on her shirt.

"Basically I'm a genetic malfunction between my parents and the creation of me and all that biology crap," said Barnett with a chuckle as she pulled her feet up onto the couch and reached for more Doritos.

CF is the result of inheriting both defective CF genes that are carried by each parent. The genetic disorder creates a buildup of thick mucus in the lung's breathing passageways and pancreas. The accumulation of mucus leads to respiratory and digestive problems as well as life threatening lung infections.

Using the elastic from her wrist she tied her hair into a knot on the very top of her head and slid off of the couch to land cross-legged on the floor in front of the wooden coffee table. Dollar store canvases were piled on the table along with a row of acrylic paint and paintbrushes. "I'm like an artsy fartsy kid. I like poetry and stuff, I doodle a lot, my books at school are atrocious," said Barnett as she reached for a paintbrush.

Staring down at her blank canvas, eyebrows scrunched, she used one finger to push her thin black-framed glasses back up her nose. "When I was younger I used to tell people that I had CF because you know, it was cool to have a problem. But now it's just something that I'd never tell

anybody. None of my friends at Carleton know," she said looking back up at me and smirking. "People pity you. I'm not dead ya know."

Barnett attends Carleton University and is currently taking linguistics. She is learning how to speak Japanese and Spanish. "The teachers know I have CF and I'm allowed to have extensions on my work but I would never use them. I always want to stay with my peers. I don't want to sulk in the corner and be like 'I can't do this,' that's why I always excel at things. Plus I take a lighter course load and take the rest of the courses in the summer because it's stressful to balance work and meds."

Waking up at 5:30 a.m. each day, Barnett starts off her day by patting herself on the chest, sides and back to loosen up and cough out the mucus in her lungs. "You can actually buy this vest thing that does the patting for you," said Barnett, propping herself onto her knees and waving her hands in different directions, showing how the vest works. "I want my dad to get it so bad. That way I can actually do things like go on Facebook or something instead of wasting half an hour patting myself."

Following Barnett across the room to the kitchen she pointed to a white machine sitting on a little table in the corner of the room. The machine has a small tube coming out from the side of it with a bent spout at the top. She grabbed the spout and held it to her mouth. "Once I'm done patting myself I have to breath into this thing for about half an hour to an hour, depending on how big of breaths I take." She sat down on the one chair at the little table "It's called a

nebulizer, it's medication to help kill the bacteria in my lungs." Barnett has to do this routine every morning and every night before she goes to bed.

"Every two years I have at least a months stay at the hospital. In Grade 5 the infection growing in my lungs was so bad that all the doctors and therapists wore masks and gloves and I wasn't allowed in the playroom. I couldn't go play soccer, which sucked the most. Apparently I was one of the first children with CF to get abscesses in my lungs. I was in isolation, I felt like an alien," Barnett remarked, ending her sentence with a laugh.

You could start to make out the detailed outline of a woman's face on Barnett's canvas. She carefully added long strands of red hair to the baldhead. "I would really like to travel someday," she said, breaking the silence. "I don't go out very much because I always have to come back to take my meds, but I'd haul all that stuff around with me to travel, and shop!"

The only place Barnett has traveled is to Disney World; the Children's Wish Foundation sent her there for a week along with her parents and older sister. "It is some of my fondest memories," Barnett said. "My school actually does a lot of fundraising for CF too," she added.

Carleton University has a lot of fundraisers for an organization called Shiner Rama, which raises money for CF. "During frosh week they approached me and asked if I wanted to donate. I did. But I didn't tell them I had it," said Barnett with a smile. "No one needs to know. I don't want others to worry about it."

After finishing her Doritos, Barnett took a handful of six pills and swallowed them all at once with the help of one gulp of water. She has to take medication each time she eats to help digest her food.

“I do get close to people but I don’t like getting too close — I also don’t have time for it. I want to focus on school and get my life straight. You tend to die at a younger age. My friend Emily died two years ago from CF, she was 22,” said Barnett. She held her paintbrush still in the middle of its stroke, “I mean everyone dies, right?”

She shrugged and smiled.

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