Faces of Mito



Challenging Assumptions and Living a Good Life with Mito: Meg Hill's journey

Meg Hill, 24, lives in St. Albert, Alta., near Edmonton. She has her own apartment, which she shares with her five-year-old tabby cat, Aria. Her boyfriend, Noah, joins her on the weekends. She loves working out, singing in her kitchen, and dancing. She's close with her family, including her parents, older sister, and two younger sisters, and enjoys hanging out with her friends and watching movies.

Meg is proud of her independence and has a friendly, upbeat demeanour. But she faces daily challenges that many 20-somethings could never relate to.

Diagnosed with mitochondrial complex 1 deficiency at age 12, Meg has used wheelchairs and walkers since she was a little girl. "My childhood was a lot of doctors' appointments and a lot of hospital visits and a lot of tests, just figuring out what I had," she says.

The journey to diagnosis

"My parents first started to get worried because I wasn't developing at the speed that a 'normal' kid would," says Meg. "I wasn't developing my walking or my speech very well. It took a long time for me to be able to properly learn to walk. I remember feeling so frustrated, how I kept falling. And it was causing me a lot of pain."

As doctors searched for answers, Meg underwent more and more testing. She was diagnosed with autism, which she did have but which didn't explain all of her symptoms or their progression.



"Nobody could figure out what it was" says Meg. "It took a long time and a lot of people trying to figure out what it was. I knew that hospital like the back of my hand."

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Adapting to life with mito

Living with mitochondrial disease, Meg faces daily challenges that include fluctuating pain and balance issues.

"I can wake up one day and be on top of the world," she says. "I'll be feeling great, cleaning my house and cooking and doing everything. And then the next day, I can wake up and I'll be in so much pain that I can't even get out of bed. It really depends on the day."

Doing a lot of walking or going for a swim can make the next day excruciating for Meg. She does her best to adapt — going out for short walks around the lake behind her apartment complex, making meal replacement shakes when cooking is too painful, and carefully planning her activities and her bodybuilding workouts around how they might affect her the next day.

"Still, it makes me upset sometimes because I can't do the things I've wanted to do," she says. She recently had to leave her job as an online grocery assistant at Walmart because it was causing her too much pain. "I was really upset about that," she says.



Beyond assumptions



Meg uses her walker and wheelchair to conserve her energy and not push her body too hard, but doing so comes with its own challenges.

"I've been bullied a lot for using equipment and I've been called names and slurs that are meant to be toward disabled people," she says.

A lack of awareness has led to many upsetting situations for Meg over the years. From having the police called on her and being drug tested because she was walking unsteadily, to being regularly approached by strangers with their intrusive questions, to having people try to take her equipment or push her in her wheelchair without permission, the experiences undermine Meg's sense of independence.

"I'm a very independent person," she says. "It makes me very upset when people don't believe me when I say I can do this on my own."

These experiences also make Meg reluctant to use her mobility aids. "It has led me to be scared of using my equipment, because I don't want to get those stares and questions from people," she says.

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Finding strength in connection

Meg's family, her boyfriend, and a best friend who has been there for her through everything help her to stay positive and to keep smiling.

"My family make me really happy," she says. "My sisters and I are really close. My youngest sister lives across the street from me and my one sister also has the same condition as I do. Because of that, I feel like we really understand each other and we can really lift each other up."

Meg wishes there were more awareness and understanding of mito, and that more people knew that a cancelled plan wasn't personal. She often keeps her symptoms to herself, hiding the extent of her pain and fatigue, and appreciates people who check in on her.

"It makes me feel special and it makes me feel seen," she says. "I wish more people would ask me, 'Hey, how are you feeling today? How are you doing today? Have you eaten?' Those sorts of questions make me feel good and make me feel like somebody actually cares."

Looking ahead with hope

Meg has come so far since her initial diagnosis. "I remember feeling so scared when I got the diagnosis because I didn't know what it meant or what was going to happen," she says. "I wish that I knew that at age 24, I would be living alone, I would be taking care of my own cat, I would be living a good life, and that there was nothing to be scared of."

Looking forward, Meg hopes to find a good job (maybe a receptionist or work-from-home position), move in with her partner, and get a bigger place and perhaps a second cat. "I have a really good. life right now and I see that only getting better," she says.



If you're a patient, parent, or loved one seeking support, MitoCanada can help.

Visit **www.mitocanada.org/support** to access a variety of support resources.

Or, reach out to us at: **info@mitocanada.org**

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MitoCanada focuses its energy on creating a world where all lives are powered by healthy mitochondria.

We use our collective energy to reduce the devastating impact of mitochondrial disease by creating MitoCommunities that are empowered, inspired and connected.