



Lily Brasch, who has centronuclear myopathy, a rare form of muscular dystrophy, lifts weights to gain strength despite her illness. (Courtesy of Born To Prove)

SOUTHERN CALIFORNIA

Woman With Rare Form of Muscular Dystrophy Defies Doctor by Hitting the Gym

By [Joe Haakenson](#) | December 14, 2021 Updated: December 14, 2021 [A A](#) [Print](#)

Getting out of bed in the morning can be difficult for some people, starting their day with a deep sleep suddenly being disturbed by a blaring alarm coming from a smartphone.

But for Lily Brasch, getting out of bed in the morning presents an entirely different kind of challenge.

Brasch, who turns 22 on Dec. 26, has centronuclear myopathy, a rare form of muscular dystrophy characterized by muscle weakness and atrophy in the skeletal muscles, which are used for movement. The simple act of getting out of bed isn’t something she takes for granted, which makes her most recent accomplishment seem miraculous.

This past September, Brasch competed in her first bodybuilding contest, a remarkable achievement and only the beginning of a journey upon which she has embarked in an effort to change the world for those who face seemingly overwhelming obstacles.

While the most obvious challenge for her would seem to be physical, it was the mental and emotional toll that ate away at her spirit.

“What I remember most from before my diagnosis, besides the physical pain and the struggles of not knowing if I could get up that morning, I lived a life full of embarrassment and full of hiding,” Brasch said.

“I did whatever I could to hide my disability. I did and still struggle, and this is a story I like to share with people to help them understand that I can wake up one morning and I can’t get the blanket off myself. I’ll have to really struggle to get out of bed.

Try Honest News \$1 for 2 months

Brasch was born in Chicago, and she still spends much of her time there, as well as in Los Angeles with her grandmother. She plans to attend college in California—likely UCLA—and eventually go to law school. For now, however, her mission is clear—to show the world that a strong mind can overcome any physical obstacle. However, the journey to get there has been fraught with pain and despair.

Doctors were unable to diagnose her disease for most of her childhood years, despite the best efforts of her parents, Joel and Mary Anne. Finally obtaining a diagnosis was the key to allowing her to find her way to happiness.

“I was 16 years old, and I was struggling a lot with my disease,” Brasch said. “I wanted to act as if it wasn’t there, but it was there, and it was progressing a little bit as I went through the normal changes of puberty. I was getting weaker.”

After many visits to several doctors, she had a muscle biopsy performed on her thigh, and her disease was diagnosed.

“I was sitting there after my diagnosis, and I asked if it was progressive, and I was relieved when they said no, it’s not progressive and life expectancy is average,” Brasch said. “So I said I’m going to go to the gym. I’m going to lift weights. I’m going to work out. I’m going to eat well. I’m going to do whatever I can to get stronger. And my doctor looked at me and said don’t do that, out of care and knowledge that she had.

“So I didn’t. Two, three years passed by and I guess I had enough. I turned to my dad and I told him if I’m going to live this life, I’ll risk injury to try to strengthen myself, try to improve my life. So even with the risk in mind I started lifting weights, and I set goals for myself.”



Lily Brasch, who has centronuclear myopathy, a rare form of muscular dystrophy, lifts weights to gain strength despite her body’s weakness. (Courtesy of Born To Prove)

She decided that she would rather die strong than live weak. It has become her mantra. In 2018, she began lifting weights, and this past September in Lexington, Kentucky, she competed in her first bodybuilding contest.

Finding a contest to compete in wasn’t easy for Brasch, who’s a practicing Orthodox Jew. Most contests take place on Saturdays, which is the Sabbath, meaning that she wouldn’t be able to compete in a contest until an hour after sundown.

Don't miss out on the latest news and updates. Sign up now for our newsletter.

Try Honest News

\$1 for 2 months

“As far as competing, I had an incredible team, and a lot of encouragement. I was ready,” Brasch said. “I had gone 20 years doing whatever I could to hide my disability, my differences, and in that moment, I felt I conquered my mind. My greatest strength is my mind. For all of us, our greatest strength is our mind, despite the quality of our body and what our bodies can do. Our minds control our future and our reality.

“So being able to walk up the stairs in the way that I do, which looks different, walk across the stage with my muscles showing, and know that I look so much different than everybody else on the stage, but still be able to do it and feel proud, was probably one of the greatest moments of my life so far in terms of my mind’s strength. It was something I’m going to remember forever. I’m going to take the lessons I’ve learned and try to teach others.”

One way to teach others is through the foundation that she has started, Fallacy of Barriers. Information about the foundation can be found on her website borntoprove.com.

“The mission is to take the mentality that I’ve applied and use every day and help others reach that same mentality inside of themselves,” Brasch said. “The concept of Fallacy of Barriers is that our barriers are a fallacy. And I interview people with barriers from around the world and bring them together to share their struggles and show others that they can break through barriers, too.”

Next up for Brasch is climbing Camelback Mountain in Arizona—a task she refers to as “my Everest.” She said it’s not about her, it’s about the message that it sends to others who feel how she once felt.

“Not only was I faced with my own circumstances, but I spent so much time by myself thinking about why I felt certain ways, and I finally conquered that. But I felt the world around me didn’t,” she said.

“So I’m here to prove that anything’s possible. I’m here to show people that, despite your circumstances, you can live the reality that you want. So ‘live weak or die strong’ is an important and powerful message. My own circumstance is what drives me to continue and to display that message, but it’s about struggles I see with others, doubting themselves because they don’t believe.

“I think the world needs this message. ... I know the world needs this message. I know I needed it. Anybody who doubts someone’s capabilities or their own capabilities, it’s because they haven’t been opened up to this understanding. I want everyone to understand that anything is possible. I will compete in bodybuilding competitions to prove that, as someone who has a muscle disease. I will climb a mountain. I will do it all.”

Copyright © 2000 - 2022

Try Honest News

\$1 for 2 months