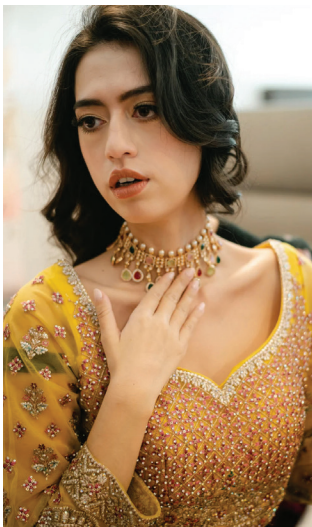


## A model with muscular dystrophy made history at NYFW — but it almost didn't happen

Abi Brasch remembers her childhood through the nightly conversations she shared with her roommate and sister, Lily. In between giggles, Lily Brasch would talk about her dreams, including the one where she put on a runway show with people of all different physical abilities, accompanied by Taylor Swift playing in the background.

But even without Swift, Abi Brasch choked up watching Lily Brasch walk at New York Fashion Week in February. To Abi Brasch, her sister was fulfilling her dream. But to Lily Brasch, it meant more than that.

On Feb. 10, Lily Brasch reportedly made history as the second person with muscular dystrophy to participate in New York Fashion Week. (NYFW did not respond to request for comment.)



Lily Brasch posing for a photo before heading to the fashion show during NYFW

"I struggled a lot mentally, more than physically," Lily Brasch tells TODAY.com about her diagnosis of a rare form of the disease. "Hundreds of people are literally telling you what they predict for your life, telling you that you can't do things and trying to paint this picture in your mind that the way you were born is flawed ... but I took a hold of that, I took charge and here I am today advocating and spreading the message that you can do whatever you want," she shares.

### 'I realized that if there was not going to be representation then I had to be it'

Lily Brasch grew up modern Orthodox Jewish in the Chicago area. A lot of her childhood was surrounded with religion, Judaism and community. She attended Jewish day school and spent weekends observing Shabbat with her parents and five siblings.

Having a mother with a Filipino background, Lily Brasch already felt unique within her Jewish community. On top of that she grew up with a disability that she says wasn't really common in her Jewish community, and if it was, it wasn't talked about.

"Despite living in that privileged environment full of kindness and love, I still felt I had to hide my disability," she says.

Lily Brasch wasn't diagnosed with muscular dystrophy until she was 16 years old. When she was born, doctors knew something was wrong, but they didn't know what. The only thing they told her parents is that she wouldn't live past 2 or 3 years old. After she did, doctors said she'd never walk.

But Lily Brasch's dad didn't accept that.

"Every day he would come home from work since I was an infant and he would aid me up the stairs just to get me to use my muscles," she says.

Lily Brasch remembers nights after she was diagnosed when she lay in the hospital or in bed at home searching on the computer "person with muscular dystrophy in the fashion industry." She would spend hours searching for anything related to disability, but everything that would come up was "just so sad."

"At one point I just stopped looking because I was feeding my mind with all this negativity that I, as someone who's experienced the condition, who's experiencing the condition, knew was not true," she recalls.

"I knew there was a lot of positivity so at that moment I realized that if there was not going to be representation then I had to be it. The next girl searching the web for someone like her I hope will find my name, reach out and I'll help them to get them placed onstage."

### The historic moment that almost didn't happen

When Lily Brasch was asked by Amna Inam, founder of Randhawa Brands, to walk in her NYFW show Brasch immediately said yes. Inam connected with Lily Brasch after one of her friends sent her a picture and video of her.



"It was really inspirational," Inam tells TODAY.com. "I said, 'OK, yes, I would love to have her for our New York Fashion Week.'"

The only problem was that the show was on a Friday night and Lily Brasch observes Shabbat. But working with her publicist and her sisters, Abi and Noa, they timed it out so Lily Brasch would walk before the holiday started at sundown.

Her sisters booked a hotel a block away from the show and her publicist, Hilary Phelps, confirmed multiple times that they'd be out the door by 5:15 p.m. But minutes before the show started, Lily Brasch was told another brand would be walking before Inam's.

As Abi Brasch stood with her sister as she was told she wouldn't walk, Abi couldn't help but cry.

"(After they told us) we sat in the corner and just like, 'OK, what now?'" Abi Brasch says. "First of all, it's so difficult for Lily to go through all the travel, makeup, dress, everything. All of her energy is at a minimum."

"I think it's the moments like that where you're pushed to see your strongest values. We thought back to my parents, who weren't there. It's Lily, Noa and I, and we're young adults figuring out our Judaism, figuring out our lives and our values and everything and all three of us were talking about how the most sacred part of our Jewish life has always been Shabbat," Abi Brasch adds.

That's when Lily Brasch's publicist worked her magic.

"I felt like a mama bear," Phelps says of her conversation with the NYFW organizers. "I was like, 'We're not leaving here until this girl walks that stage, do you understand me?'"

"There were people there that made it happen and made some changes and Lily got to walk and then we walked out the door and got to the hotel in time for sundown," Phelps adds.



Noa Brasch saw in that moment how despite the obstacles her sister never sacrificed her faith.

"I hope that any Jew, and specifically women, if they feel like, you know, the minority within this religion, they

can do the things they love and they can accomplish the things they want and they can be successful and still hold that religion so dear to their heart," Noa Brasch says.

### Getting up and choosing to be strong

Dressed in a yellow lehenga, Lily Brasch rolled out onto the stage in a wheelchair, opening the show. Then, she got up.

"I wanted to show with the wheelchair is that I got up and I chose to be strong," Lily Brasch says.

One of the models, CJ Chang, accompanied Lily Brasch down the runway. The moment felt surreal for her. But she was also nervous.

"I was worried about what I would look like, how would people react, especially with the message we were trying to show, which was me getting out of a wheelchair and walking, which is my story and the story of many others," she says.

"I didn't want people to pity me, but when the day of the show came, I became very excited. Something in my mind switched and I know firsthand that people are getting inspired to get out of bed the next day when they see something like this," she adds.

Inam reminisces on how people were crying as Lily Brasch rolled onto the stage in a wheelchair.

"The crowd was inspired," Inam says. "It's an inspiration for everyone, including me. It was a great experience and people were really excited. I'd love to have her again."

### 'I honestly believe that anyone can do anything. I believe it so much that it just fires me up'

Being a role model for anyone struggling with disabilities, specifically in the Jewish community, is Lily Brasch's mission in life. The message she hopes to spread is for people to never tell someone they can't fulfill their dreams. For her, that was being able to walk.

Every day she trains, whether that be swimming or strength training. It's not so much trying to prove anyone wrong, but instead showing people the power of mental strength.



"I honestly believe that anyone can do anything. I believe it so much that it just fires me up," she says, mentioning "Born To Prove," an organization she started that she uses to share her story with muscular dystrophy online.

While the NYFW moment was historic for Lily Brasch, her sister Abi notes it was never about her disease or what she couldn't do. Instead, it was about her sister's determination to fight for what she believes in.

"As she walked the runway, she, No. 1, revealed to the entire world some of her deepest insecurities and weaknesses but also showed the level of strength she has and her dreams and what she's going to be continuing to do for the rest of her life," Abi Brasch says.

"The world is not yet accommodating for everyone. It's not. And to fight this system every single day is not something people see unless you lived it. That's why I'm so proud."