

Profile: Daniela Delgado



Daniela Delgado has been putting smiles on the faces of sick children by making custom birthday cakes with the help of her mom and dad for the past 11 years.

By Trudie Mitschang

Trudie: Tell us about your diagnosis.

Daniela: When I was 6 months old, I was diagnosed with severe von Willebrand disease type 2 (VWD), the same disorder my mother has. I was covered in bruises when I was a baby, and my pediatrician asked my mother if she had a bleeding disorder. That's when they confirmed I also had it.

Trudie: What is your treatment plan?

Daniela: Initially, I had to infuse clotting factor medication twice a week, and now during my periods, I have to infuse every day. I also take tranexamic acid pills during my cycle three times a day to manage potential blood clots.

Trudie: How has living with chronic illness impacted your life?

Daniela: While growing up, seeing my mother have so many bleeding episodes and also bleeding myself was very difficult. It's hard for two people at home living with the same illness, but I am lucky my mom knows what I am dealing with and that she can understand my frustration and pain. I also was diagnosed with another chronic condition called Ehlers-Danlos syndrome, which is very painful. As a young person, I have to limit physical activity because it causes internal bleeding (people with VWD also have microbleeds and internal bleeding in joints and other parts of the body). I had to stop all sports and activities for a while, and at one point when I was 9 years old, I was bleeding for three consecutive months. More recently, I bled for six months straight. I am currently trying to use an intrauterine device to control my bleedings while also continuing my clotting factor and tranexamic acid pills.

Trudie: Tell us about your love for baking.

Daniela: Mom and Dad were cake decorators, and when I was 4 years old, I was "helping" them with a cake when I took my magic wand (the spatula) and made a wish. I wished I could bring some smiles to other kids who live in pain and have very difficult times at a young age. I promised myself I would help others because this is the best part of living. With the help of Mom and Dad, we founded Daniela's Little Wish.

Trudie: How is your organization supported financially?

Daniela: For many years, my parents economically supported Daniela's Little Wish. They provided all ingredients, supplies and tools, and they were also the cake art experts, helping to transform a simple cake into something magical for each child. Now that Daniela's Little Wish is a nonprofit organization, people can make monetary donations through the website www.danielaslittlewish.org by sending a check or paying with Venmo or PayPal.

Trudie: How do you promote your services?

Daniela: My parents continue donating their time and expertise, and they travel with me when I deliver motivational speeches around the country for children with severe bleeding disorders. I usually spend a few hours a week on social media looking for kids with hardships, and I contact their parents to ask if they want a birthday cake. Also, some parents who have been told about Daniela's Little Wish contact me via email or messenger. If I am going to the grocery store or just driving

WHEN SHE was just 4 years old, Daniela Delgado made a wish: She recalls being in the kitchen with her parents and waving a green spatula in the air, saying "This scraper is my magic wand, and I want to make cakes for sick kids!" That "wish" became a hobby, and the hobby became a full-fledged nonprofit named Daniela's Little Wish. Today, this 15-year-old Sandy Hook, Conn., resident — who herself lives with two chronic disorders — lovingly creates custom birthday cakes and other specialty treats free of charge to children living with severe illnesses. Her tagline: "Baking Smiles for Kids Since 2011."

Editor's note: To learn more about Daniela's Little Wish, visit www.danielaslittlewish.org or follow Daniela on Facebook or Instagram.

around and see a child who is possibly a candidate for a cake, I ask my mom or dad if they can go with me to talk with the parents about my mission and to give them a business card in case they decide to order a custom cake.

Trudie: What inspires your cake designs?

Daniela: We offer custom cakes for children and their families to celebrate the most important day of their lives: their birthday! We customize each cake based on favorite flavors and colors, or create designs based on movies, cartoons or hobbies. Each character that goes on the cake is freshly handmade and edible, and we spend between eight and 10 hours making each cake. Sometimes we spend more hours, to be honest, depending on the difficulty of the design. Dad is the artist and, after work, he helps with the characters until very late at night. Mom is the expert in fillings, buttercream and fondant, so the three of us working as a team make our clients' wishes a reality.

Trudie: Tell us about your advocacy work and awards.

Daniela: I went to Washington, D.C., and met with local officials and members of Congress. Because I am the next generation advocating for my community, I believe it is my responsibility to push for better diagnoses, treatments, health plans and medications for the thousands of patients with rare diseases. I was honored with the National Organization for Rare Diseases Rare Impact Award in 2021 for my 10 years of advocacy for the bleeding disorder community. I also received the Teen Impact Award in 2021 for my mission to empower people of all ages to be the best version of themselves and to not let anyone stop them. In 2020, I was honored with the Ryan White Youth Award from the National Hemophilia



For her advocacy work through her nonprofit Daniela's Little Wish and motivational speaking, Daniela has been honored with several awards in the past few years.

Foundation for helping to educate those with bleeding disorders and the general population about bleeding disorders. Ryan White is an icon in our community. He had severe hemophilia and contracted HIV and hepatitis C with contaminated factor medication in the 1980s. He passed away at 18 years old.

Trudie: How do you stay motivated and positive?

Daniela: My motivation comes from my illnesses and pain, and from seeing my mom suffering and my dad helping and supporting us. I don't want my illnesses to define who I am. Maybe I can't always live life to the fullest, but I need to live the best way possible. That is why I continue my treatments every week to stay "healthy" and to transform what could be incapacity into inspiration for serving others.

Trudie: What do you wish people knew about chronic illness?

Daniela: I wish people knew how frustrating it is to hear all of the common comments and questions: "But you don't look sick at all!" "You look fine to me." "Weren't you at the hospital yesterday?" "I thought you were in a wheelchair." "You don't look as sick as you say you

are." Those are all misconceptions about chronic illnesses. The worst part is not the pain, medication or the actual disease. The worst part is being judged by others who believe we look healthy, when only we know the excruciating pain or difficulties we are suffering. I've learned in these instances that we have to stand up for ourselves and others. We have to educate people about our chronic diseases, especially if they are invisible.


Trudie: What are your goals for the future?

Daniela: My goals are to continue to bake smiles for kids and to touch many souls with my motivational speaking. I will advocate for others until my last day on Earth.

Trudie: What are your hobbies when you are not in the kitchen?

Daniela: I love to study. I want to be good in whatever career I choose and always offer my best to others. I love to read novels, biographies and history, and to laugh and make friends. I am learning about other cultures, and I hope to visit new countries to experience other beautiful, diverse human beings. I also love to try food from different countries.

Trudie: Who is your support system?

Daniela: I have incredible parents who are my main support, my structure, my confidantes, my everything. I also have a close group of friends who know about my condition and care about me. I meet amazing people through Daniela's Little Wish who are always there for me. 



TRUDIE MITSCHANG is a contributing writer for *IG Living* magazine.

Editor's note: While Daniela doesn't have an immunodeficiency disorder, she does live with two chronic disorders, which are managed by infusions and daily medications. Her story is both relatable to and inspiring, and we hope it encourages readers on their own chronic illness journey.