



**Genome readers honor genetic counselors
who interpret complexity with compassion.**

Made possible by



ALLISON



Winner

Allison Goetsch

Going the Distance

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Twenty-four years, hundreds of doctors, and countless genetic tests later, and I finally, with the help of my dedicated and patient genetic counselor, Allison, found an answer. A diagnosis! No longer am I a patient with an “undiagnosed genetic condition,” and Allison was a driving force in this becoming a reality.

I was born prematurely with many other obvious signs that something wasn’t quite right. Since then, I have had more than 10 brain surgeries, three spinal fusions, hundreds of days in the hospital, and more doctor appointments than I can count. I have a sister who passed away at age 5 from an aneurysm. I knew I had a genetic condition, but I never knew what type. I always wondered if there was a connection between my sister and me.

After years and years of testing and always hearing results like “inconclusive” or “negative,” I became weary of the process. I started to remove myself from the genetics department and ignore the appointment reminders. I resigned myself to never knowing my condition.

Luckily, I was blessed to be assigned to Allison, who reached out to me during one of my follow-up appointments in the hospital. She continued to do this for a while, and she always was so positive and encouraging. She brought new suggestions, new test options, and more information. All of this is key to any genetic counselor’s role.

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However, more importantly, Allison renewed our hope that one day we would have an answer.

I began going to my genetic appointments again and began opening the line of communication between the department and me. I tried new tests and continued my search for a diagnosis. Through all of this I have come to find there is a special bond between genetic counselors and their patients — one unlike any other that I’ve had in the hospital.

Allison cared about my well-being as a whole person — not just the person she knew from my medical records and test results. She took the time to ask about my life outside of the hospital.

She also made sure that I was okay whenever there was a chance of a new diagnosis. If she thought that a test would come back negative, she made sure not to get my hopes up too high, by thoroughly explaining what we were testing for and how likely it was to find an answer. On the other hand, she constantly reminded me that eventually we would find an answer and that she was working tirelessly to help me do that.

As a genetic counselor, she had to wear so many hats: intelligent genetics department staff with facts to deliver, translator to repeat those facts in English, caring psychologist to help me cope with the

lack of a diagnosis, and supportive friend. I knew how much she cared about me and how hard she was working to help find a diagnosis.

I will never forget the day when she finally got to tell me something different.

“So, I almost dropped the files when I got them back from the lab, but we found something. We have a diagnosis!” she said. She was as excited as I was, and she shared in my joy.

She also brought every piece of medical journal literature about the syndrome to show us. She gave us every detail on the condition and information about the other nine patients in the world that have this condition. She answered every question we had to the very best of her ability.

She even talked through my family planning options, something my mom could never even fathom talking about yet, and made sure that I felt comfortable with all of the new information we had just received. Without Allison, I wouldn’t have a diagnosis. Without Allison, I wouldn’t be able to say that my medical history will be published for others to learn about the syndrome, which will hopefully save many lives in the future.

To an amazing person and genetic counselor, thank you, Allison, from the bottom of my heart. 🧡

