



**Social Media Post**  
samples

“If you want peoples’ perceptions to change, then it’s important to share your story. I hope my story will help people better understand rare disease and be more compassionate to others like me in the future.”

– Elle



adrian



"The first step is awareness."



the **Rare Majority**  
project

christine



"Everyone should feel like they are able to tell their story."

dale



"Rare disease is a common human experience."

the **Rare Majority**  
project



savannah

"Jonah was fearfully and wonderfully made, and I would not change anything about him."

“I know how scary it can be to not know what’s happening to you and to have no name for what’s controlling your life.”



“It can be a huge relief to just have a name and a diagnosis.”  
-Olivia

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**OLIVIA**

Olivia has Kleine Levin Syndrome, a rare neurological disorder that causes her to sleep for up to 22 hours a day. Some of Olivia’s biggest supporters have been the incredible nurses who helped care for her when she was hospitalized.

Olivia is a student at Calvin University. She loves to paint, hand letter, and do crafty things like refurbish furniture.



Inspired by the nurses who have walked with her on her rare disease journey, Olivia hopes to become a pediatric nurse herself.

Read more of Olivia’s story:  
[calvin.edu/research/rare-disease/rare-stories/rare-majority](https://calvin.edu/research/rare-disease/rare-stories/rare-majority)

**Instagram Story**  
samples

“It is hard for people to understand how debilitating a rare condition can be when you look fine.”



“Rare diseases can make you feel isolated when the people around you do not understand the effects of the condition you are living with.”

-Greta

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**GRETA**

Greta has hypermobile Ehlers Danlos Syndrome, which is an invisible illness. It took her a while to tell her story because her doctors did not believe she was ill. She is sharing her experience now so that her rare condition can be better recognized and understood.



Greta is a student at Calvin University. She has three sisters and enjoys teaching Sunday school, reading, discussing philosophy, and playing games. She began playing the harp when she was four.

If she was an ice cream flavor, she would be spiced vanilla because when people first meet her, she comes across as reserved, but when you get to know her, her true personality comes out.

Read more of Greta's story:  
[calvin.edu/research/rare-disease/rare-stories/rare-majority](https://calvin.edu/research/rare-disease/rare-stories/rare-majority)



“1 in 10 people have a rare disease. That challenges the definition of what normal is. Rare disease is a common human experience.”

Dale is a graduate of Calvin College, as are his wife and three daughters. He was diagnosed with a rare disease in 2012. He enjoys reading about science and has a particular interest in climate change. If he were an ice cream flavor he would be butter pecan because he is a little old fashioned and a little intellectual. He has held several leadership positions in commercial HVAC engineering and design at Trane Creative Solutions.

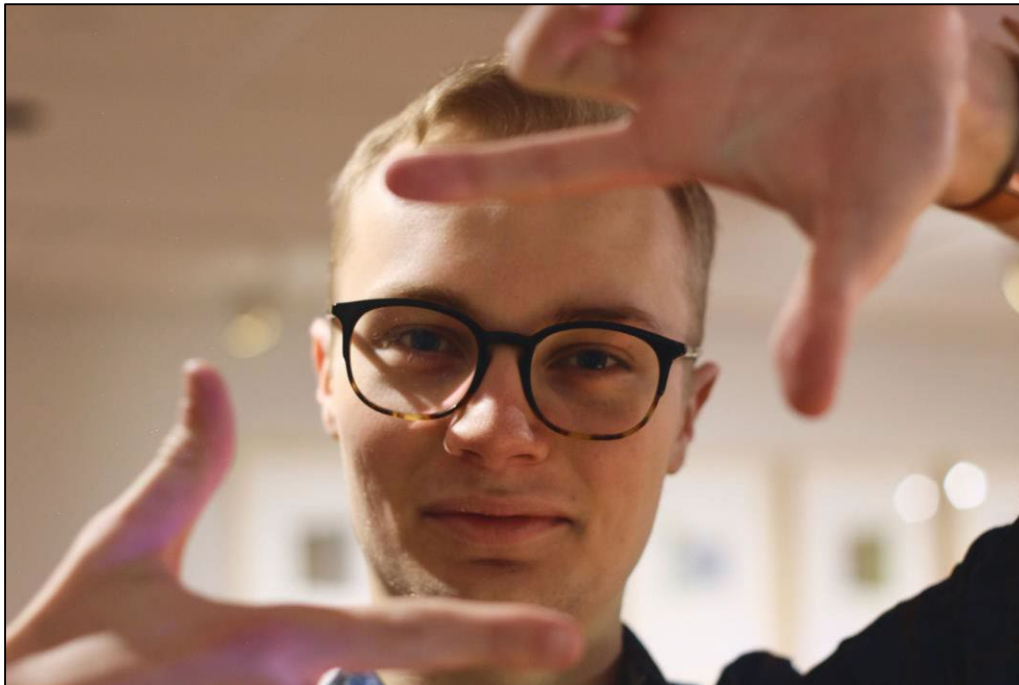
One of the challenges of having a rare disease has been giving up things that he used to do including running and playing basketball. He would like to challenge people to be curious and be willing to adjust their definition of what normal is.

Read more: [calvin.edu/research/rare-disease/rare-stories/rare-majority](https://calvin.edu/research/rare-disease/rare-stories/rare-majority)



Physical Display  
samples

“We shouldn’t treat people with rare diseases any differently because of their conditions, but we should be understanding, sensitive, and supportive. The first step to that is awareness.”



Adrian is a film and marketing major at Calvin University. He has two sisters, one older, and one younger. Adrian loves photography and videography. He blurs the lines between job and hobby by working as a freelance photographer. He is also on Calvin’s improv team and enjoys watching and performing with Calvin Theater Company.

Adrian has a rare disease called spherocytosis. He considers himself lucky because it does not have a significant impact on his daily life. He thinks it is important for people to understand that while not all rare diseases cause constant struggles, they are still significant. 1 in 10 people has some sort of rare disease, so it is something that we should all be conscious of.

Read more: [calvin.edu/research/rare-disease/rare-stories/rare-majority](https://calvin.edu/research/rare-disease/rare-stories/rare-majority)

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