

## Children's Book Series is Inspired By Patients Living with Rare Diseases

June 30, 2023

At Alexion, our mission is to transform the lives of people affected by rare diseases and one of the tangible ways we raise awareness is by developing tools and resources to educate about the impact of rare diseases on patients, caregivers, and families. Beginning in 2021, Alexion has partnered with the broader rare disease community to create the **Inspired By** book series, a collection of stories to help families with young children talk about rare diseases in an approachable and age-appropriate way.



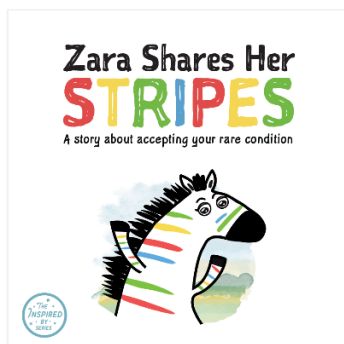
Alexion launched **Inspired By** with the introduction of the first book in the series in June 2021.

**Klara's Talent** was inspired by Rachel, a real mom living with generalized myasthenia gravis (gMG), a debilitating, chronic, and progressive autoimmune neuromuscular disease.<sup>1</sup>

While speaking with Alexion, Rachel wondered aloud how she would explain gMG to her young daughter, saying, "I wish there was a book I could read to her." In that moment, *Klara's Talent* was born.



The second book, **A Day with Nurse Jen**, is dedicated to young patients and families affected by atypical hemolytic uremic syndrome (aHUS), a genetic, chronic, rare disease that can progressively damage vital organs and can lead to stroke, heart attack, kidney failure, and death.<sup>2</sup> *A Day with Nurse Jen* is inspired by Jennifer, a pediatric nurse who supports children and adolescents living with aHUS.



The third book, **Zara Shares Her Stripes**, is a story about accepting your rare condition and finding a supportive

community. The book was inspired by three members of the rare disease community—Deja, who lives with gMG; Kristin who lives with neuromyelitis optica spectrum disorder (NMOSD); and Anndria, whose daughter lives with a deficiency of argininosuccinate lyase (ASL).



***Let's Make a Memory***, the latest book in the series, is a story based on Arlin, a real-life mother and physician living with NMOSD, and her daughter. The book recounts their experiences and conversations, as the daughter in the story comes to better understand how her mom's rare autoimmune condition impacts her day-to-day life. The story demonstrates that while living with a rare disease certainly comes with challenges, this does not mean it has to be a barrier to making wonderful memories with the people you love.

The ***Inspired By*** series embodies Alexion's commitment to the rare disease community and to raising disease awareness among people of all ages. To order a complimentary copy of any book in this series for yourself, for someone you know affected by a rare disease, or for a patient support group, please visit [AlexionInspiredByBooks.com](https://AlexionInspiredByBooks.com).

#### References:

1. NORD. Myasthenia Gravis. Available at: <https://rarediseases.org/rare-diseases/myasthenia-gravis/>. Accessed June 2023.
2. NIH. Atypical hemolytic uremic syndrome. Available at: <https://rarediseases.info.nih.gov/diseases/8702/atypical-hemolytic-uremic-syndrome>. Accessed June 2023.