

New Book Series for Children Inspired by Patients

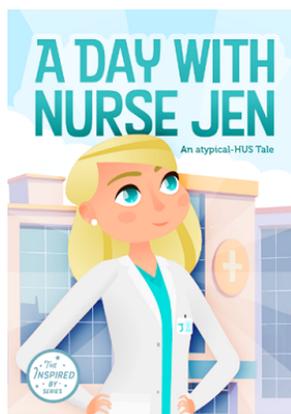
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One of the tangible ways we work to raise disease awareness is by developing tools and resources to help educate patients, caregivers, and families about rare diseases. Inspired by patients for patients, Alexion has partnered with the broader rare disease community to create the Inspired By book series, a collection of stories that aim to help families with young children talk about rare diseases in an approachable and age-appropriate way.



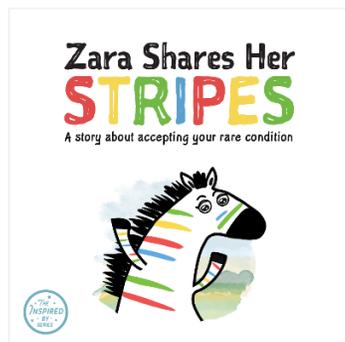
In June 2021, Alexion introduced the first book in the Inspired By series, *Klara's Talent*, during MG (myasthenia gravis) Awareness Month in the United States. *Klara's Talent* was inspired by Rachel, a real mom living with generalized myasthenia gravis (gMG), the more severe and generalized form of MG, a debilitating, chronic, and progressive autoimmune neuromuscular disease.1-4

While speaking with Alexion in 2019, 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 in the series, *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 either be caused by genetics or a trigger that can progressively damage vital organs that can lead to stroke, heart attack, kidney failure, and death.5-6

A Day with Nurse Jen is inspired by Jennifer, a pediatric nurse who supports children and adolescents living with aHUS.



In February 2022, in honor of Rare Disease Day, Alexion released the latest book, *Zara Shares Her Stripes*, a

story about accepting your rare condition. 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 argininosuccinate lyase deficiency (ALD)—this third book in the Inspired By series celebrates the unique gifts that come with living with a rare condition and finding a community with whom to share those gifts.

Like *Klara's Talent* and *A Day with Nurse Jen*, *Zara Shares Her Stripes* embodies Alexion's commitment to the rare disease community and raising disease awareness among people of all ages.

To order a complimentary copy of *Klara's Talent*, *A Day with Nurse Jen*, or *Zara Shares Her Stripes* for yourself, someone you know affected by a rare disease, or for a patient support group, please visit AlexionInspiredByBooks.com.

References:

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5. Benz K, Amann K. Thrombotic microangiopathy: new insights. *Curr Opin Nephrol Hypertens*. 2010;19(3):242-247.
6. Tsai HM. The molecular biology of thrombotic microangiopathy. *Kidney Int*. 2006;70(1):16-23.