



## 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.



With June being MG (myasthenia gravis) Awareness Month in the United States, Alexion is pleased to introduce the first book in the Inspired By series, Klara's Talent. 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. 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.

In the story, Mommy Koala cannot attend her daughter Klara's talent show due to her gMG symptoms, so Klara adapts and brings the show to her mom instead. Using rhyme and comforting illustrations, the book explains that even though gMG can make simple activities difficult, for some families, managing gMG is a normal part of life.

To order a complimentary copy of Klara's Talent for yourself, someone you know affected by gMG or a gMG support group, please contact Alexion at [OneSource@alexion.com](mailto:OneSource@alexion.com) or 1.888.765.4747.

The next book in the Inspired By series will help explain atypical hemolytic uremic syndrome (aHUS) and will be released late summer 2021.

### References:

1. Huda R, Tüzün E, Christodoss P. Targeting complement system to treat myasthenia gravis. *Rev Neurosci*. 2014;25(4):575-583.
2. Howard JF, Barohn RJ, Cutter GR, et al. A randomized, double-blind, placebo-controlled phase II study of eculizumab in patients with refractory generalized myasthenia gravis. *Muscle Nerve*. 2013;48(1):76-84.
3. National Institute of Neurological Disorders and Stroke. Myasthenia gravis fact sheet. [http://www.ninds.nih.gov/disorders/myasthenia\\_gravis/detail\\_myasthenia\\_gravis.htm](http://www.ninds.nih.gov/disorders/myasthenia_gravis/detail_myasthenia_gravis.htm). Accessed September 25, 2019.
4. Meriggioli MN, Sanders DB. Autoimmune myasthenia gravis: emerging clinical and biological heterogeneity. *Lancet Neurol*. 2009;8(5):475-490.