Listening And Learning From The Rare Disease Patient

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In the world of rare diseases, where so many conditions remain undiagnosed and untreated, we take seriously the opportunity to really listen to and learn from patients and caregivers and their healthcare providers.

By Anne-Marie Law, Chief Human Experience Officer
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At Alexion, innovation includes really focusing our collective efforts to strive toward understanding patients' needs, including meaningful therapies and beyond. We are focused on innovating in all we do to improve the day-to-day experience of people living with a rare disease.

This is particularly evident in our most recent FDA approval for the first medicine for neuromyelitis optica spectrum disorder (NMOSD), a rare, devastating and chronic autoimmune disorder of the optic nerve and spinal cord.

Our innovation in NMOSD first started in 2009 with a group of dedicated researchers and brave patients who paved the way. We are deeply thankful for all of the patients who participated in the clinical trials.

Truly transforming patient experience with this disease means delivering a medicine and more. It means actively listening to them, their caregivers and their healthcare providers to deliver services and support to address their needs.

Recently, we hosted Sumaira Ahmed, founder of the Sumaira Foundation, which is dedicated to "Illuminating the darkness of NMOSD." Sumaira shared her story with our employees, including what the healthcare community needs to understand about a person's experience after receiving this diagnosis.

Sumaira makes an impression on you from the moment you meet her: she's a self-described fashionista with a vibrant personality and dreams of becoming a Bollywood actress. When I met her, I was both blown away and humbled by her energy and drive.

When Sumaira started having vision issues for which she had no answer she visited multiple specialists. As her vision worsened Sumaira faced a hard truth: she was seriously ill, scared and needed answers. After additional evaluations, she learned she had NMOSD. True to her nature, Sumaira channeled this diagnosis into new purpose.

Sumaira shared her emotional journey with us, from the frustration of the initial diagnosis and worry about her future, to the fight for answers, the fatigue and isolation of learning how to manage the disease, and the desire to be a part of the decision-making process. She felt there was limited support or information for people living with the disease and took matters into her own hands by launching her own foundation to provide resources for the patient community.

We learned a lot listening to Sumaira and other NMOSD patients as part of our own Alexion journey. We know that living with a disease like NMOSD is not just about the medicine. As a leading rare disease partner, we can and should step up with support services that not only help people living with the disease manage through the day, but help them live their best lives. And so, as we partner with NMOSD community, we are committed to continued collaboration to build innovative tools and networks that answer their call.