It is often said that it is not the challenges that define us but how we respond to them. The COVID-19 pandemic has certainly challenged our global healthcare system and with it, left one of our most vulnerable populations, the rare disease community, at risk. And yet, it has also brought opportunity – the opportunity to change the systems around us and redefine how we innovate for, engage with, and serve people affected by rare diseases.

To change the systems around us, we must first change the conversation and the Milken Institute, a nonprofit, nonpartisan think tank that helps people build meaningful lives, aims to do just that with its annual Future of Health Summit. The Summit brings together global leaders to confront the most significant health challenges by matching diverse resources with innovative and impactful ideas. This year, the focus will be on the converging crises of public health, economic insecurity, and social injustice that have been brought into sharp focus as a result of the COVID-19 pandemic. Alexion’s Senior Vice President of Research, Sharon Barr, and Senior Director of Health Policy, Lisa Feng, will be at the Summit to discuss the impact of these crises on the rare disease community and how Alexion is engaging patients and driving innovation to create a more equitable healthcare system.

At Alexion, our innovation begins with listening. In meeting with patients and listening to their stories, we learn what makes each of them unique. At the same time, we learn that many of their stories share a common theme: the journey to diagnosis is long. With 7,000 known rare diseases in the world, it can take an average of 4.8 years and 7.3 specialists before a patient receives an accurate rare disease diagnosis, and even then, only 5% have an approved treatment option. To close this gap, Alexion is collaborating with external partners to leverage
our investments in data and artificial intelligence to build scalable solutions that will substantially shorten the journey to diagnosis and connect patients with answer sooner. As part of their conversations at the Summit, Sharon and Lisa will talk about the future of diagnostic innovation and the partnerships and policies that are needed to make these platforms more broadly accessible across the rare disease ecosystem.

Alongside the Summit, the Milken Institute publishes a collection of essays, known as Power of Ideas that are written by a diverse group of influencers to convey their thoughts on building meaningful lives, driving shared prosperity, and more. As part of this year’s series, the Milken Institute published an essay written by our President and CEO, Ludwig Hantson, Ph.D., in which he presents the idea that our ability to change the systems around us lies in recognizing the humanity in each of us. At Alexion, we are committed to creating a more connected and equitable system, designed with patients at the center, and it starts with understanding the people we serve. By engaging patients early and often, we can make better-informed decisions and provide greater support to them and their families.

It is conversations like those being had at the Future of Health Summit, centered around innovation and collaboration, that enable us to change the systems around us but it is the conversations we have with patients that inspire us to do so. As Ludwig writes in his essay, “We recognize that we can best serve patients when we truly listen to patients.”