

Begin to immerse yourself by listening to two of the stakeholders in this hypothetical example. Click to listen to their stories and then scroll down to continue experiencing the simulation.

PART 1 LISTEN

to the stakeholder stories

Click here to listen to Eli & Dr. Jagtap tell their stories



Eli Scott-Hoppin
Child/Patient
(He/Him/His)

“Until a little while ago, I was excited because my parents promised to get me a dog, which I’ve been wanting forever. But then I learned about Ninja Teen Force Extra, a TV show from when my Dad was a kid that I’ve been watching with him on YouTube.

Since I got sick, I don’t feel like going outside at all and would rather stay inside and catch up on old episodes of Ninja Teen Force Extra on Dad’s iPad. I’m frustrated, but it’s hard to explain to mom and dad that I really still want to do karate classes, even though I don’t always feel like practicing right now.”



Dr. Jagtap
Pediatric Hematologist
(He/Him/His)

“I am a Pediatric Hematologist at the University of Eastopolis Hospital. I’m usually the first stop for patients after specific concerns are raised by their primary care physicians, and I see any number of patients on a daily basis. After I work with them there, they might be sent to any number of other specialists; I am typically one of the many doctors patients might find themselves having to interact with.

The severity of Eli Scott-Hoppin’s symptoms stuck out to me. He’s a patient who I understand is being seen by the hospital’s Head of Nephrology.”

PART 2 READ

an excerpt from Eli’s diagnosis journey

Dr. Masoud flipped through the charts and documents sent to her from the Emergency Room and the Intensive Care Unit about Eli Scott-Hoppin.

As she continued to read her mind raced through branching trees of symptoms and possible diagnoses. The test results were unusual. The symptoms had troubled everyone along the chain to this point. What had looked like a bad stomach bug to the parents had become much more complex. The strange combination of neurological impairment, the convulsions, the bloody diarrhea, and now renal failure. The possibility of a genetic factor couldn’t be ruled out.

When she arrived at Eli’s room, she saw the tired, faces of two terrified parents, Robert and Rachelle, and the small, sleeping form of a child. Dr. Masoud smiled, introduced herself, and gave them what information she could provide, information that these two desperately wanted.

Dr. Masoud
Pediatric Nephrologist
(She/Her/Hers)



She explained to them that she and her colleague Dr. Jagtap had ordered some tests, but that their son’s kidneys were failing. They would have to move quickly to save Eli’s life.

She tried to lay out that this might be a long journey, ruling out possibilities to find the answers, a diagnosis by exclusion. With so much to do, the place to start was with naming what was happening. His symptoms indicate Thrombotic Microangiopathy or TMA. Now it was crucial to understand the kind of TMA. One culprit might be atypical Hemolytic Uremic Syndrome, aHUS. She had ordered a number of tests; it would take some time to get the results.

Dr. Masoud saw the two of them look at each other, quietly, taking in what they had learned. What it would mean for their son and for their own lives? They all stood quietly in the room while the little boy quietly slept, a shape in the blankets.

Eli’s Stakeholder Ecosystem



PART 3 REFLECT

Now that we’ve learned a bit about Eli’s journey, and two of the doctors involved in his care, spend a moment and reflect on the following questions. There are no wrong answers here.

1 What might these stakeholders be feeling and doing?

2 How could you have a positive impact on the patient journey for someone affected by aHUS?

Thank you for experiencing a moment that matters in Eli’s journey