

CHILDREN'S HEALTHCARE OF ATLANTA

# Improvise, Adapt, and Overcome

BY AMY MEADOWS

To 24-year-old Asha Kumar, Dr. Fernando Burstein is like family. It's not surprising; she's known him since she was two days old. Only 48 hours after her birth, she was brought to Burstein, medical director of the Center for Craniofacial Disorders at Children's Healthcare of Atlanta. He knew then that he would become a significant

person in her life; she had been diagnosed with Apert syndrome, a genetically transmitted disorder that causes abnormal development of the skull.

"Apert syndrome is a rare disorder that happens in utero and causes deformities as a baby grows," Burstein says. "And it was especially unusual in Asha's case because she

didn't have a family history of the syndrome. A spontaneous mutation resulted in her Apert syndrome."

To date, Kumar doesn't know how many surgeries she's had. "When we discuss it among our family, my mother always says it's about 60 plus," Kumar says.

Those surgeries began when she was one month old and have varied in complexity over the years. When she was younger, the surgeries were very serious: reshaping her skull, increasing the space within the skull to allow for her brain's growth, moving her eye sockets to correct wide-spaced and bulging eyes, widening the upper jaw, reshaping her nose so she could breathe properly, and forming her fingers and toes, among others. Many of the surgeries were necessary to avoid complications such as blindness or mental retardation. "Asha's condition went according to script," Burstein says. "Everything she experienced was characteristic of this complex deformity. And with something like this, you do surgeries in stages. Some come at one age, and some come at another."

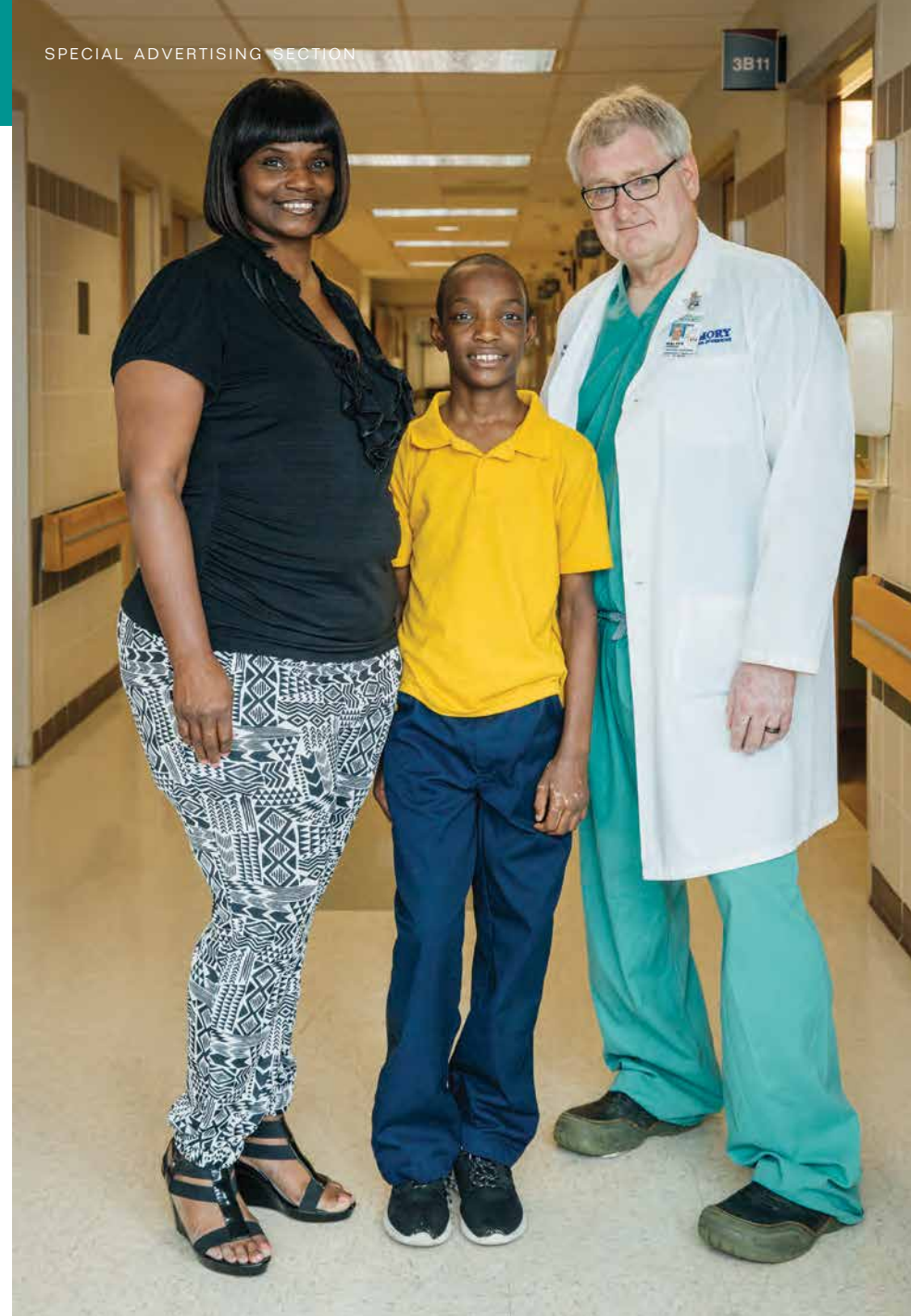
As Kumar moved from surgery to surgery, she never really thought about the fact that she had to endure such extreme obstacles—and spend so much time in the hospital—as a child. "I didn't know any different," she says. "For me, it was normal. And from the beginning, my parents made sure that I had a normal childhood. I have two older siblings, and they didn't want me to feel different from anyone I knew or interacted with. They put me in activities and allowed me to play. They didn't want to stop my education for any reason. And I wanted to take advantage of all the opportunities

I could gain out of my school years."

Kumar has a bachelor's degree in psychology from Georgia Tech and currently is studying for her master's degree in rehabilitation counseling at Georgia State University. Her major surgeries are behind her, and she's focused on what's next, like that doctorate she wants. As she moves forward with her life, she maintains a close relationship with Burstein and the team at Children's Healthcare of Atlanta. "Surgery and illness and disability are not enjoyable" she says. "But Children's is a great hospital, and they've created such an enjoyable, child-oriented environment. And Dr. Burstein is just wonderful. When I'm talking to him, I'm completely at ease."

For Burstein, who has worked closely with Kumar's entire family for the past two decades, the feeling is mutual. "You don't ever want to bet against Asha," he says. "She can do whatever she wants to do. And it's wonderful to see her now. Her family never gave up. They asked the right questions, and when they saw progress, they were encouraged. They worked together to make her life as successful as possible."

"I feel like my story isn't really that amazing," Kumar says. "This is something I've always had. I learned to figure it out. You just have to adapt to whatever is around you." +



GRADY HOSPITAL

## A Sense of Relief

BY AMY MEADOWS

In an instant, your whole world changes," says Dr. Walter Ingram, medical director of the Grady Memorial Hospital Burn Center. "One minute, you're worrying about school and other issues. Then your child is burned, and you're in the hospital. You have to try to get your head around it."

That's exactly what Tyronna Nolley and her husband, Uland, faced on November 13, 2014. When their 9-year-old son, Tyron, went into the kitchen to get some hot sauce from a high cabinet, he decided to use the oven as a makeshift stool. He opened the door and stepped on it, assuming it could