



A Child's Legacy

How one neurologist's experience as a parent transformed her practice.

According to the 2007 National Survey of Children's Health, 7.4 million American children from two to 17 years of age have one or more emotional, behavioral, or developmental conditions. These include attention deficit disorder, depression, anxiety problems, behavioral or conduct problems, autism spectrum disorders, developmental delay, or Tourette's syndrome. A child with these or other chronic neurologic problems—such as seizures, migraine, and traumatic head injury—faces many challenges. So does the child's entire family.

Finding the right diagnosis and treatment for children with chronic neurologic diseases can be a monumental task. That challenge is compounded by the emotional toll of having a child who is living with a chronic illness and the stress caused by multiple doctors' visits, the need for taking medications, the side effects of those medications, and limitations on participating in typical childhood activities.

Many such children have touched my life. In this issue of *Neurology Now*, we cover some of the challenges facing children with fragile X syndrome ("Fragile X Syndrome," page 37) and describe the hope afforded by new breakthroughs in medical research.

I want to tell you a story about a friend and colleague, Carlayne Jackson, M.D. Dr. Jackson is a neurologist and an internationally renowned specialist in nerve and muscle disorders, a professor of neurology at the University of Texas Health Science Center at San Antonio, a Fellow of the American Academy of Neurology (AAN), and a newly elected member of the AAN Board of Directors.

"My son Christopher was born during my first year of neurology residency with a chromosomal deletion that resulted in profound developmental delay, epilepsy, deafness, and blindness," Dr. Jackson says. "He had to be taken to specialists in pediatrics, neurology, gastroenterology, pediatric surgery, orthopedics, genetics, and cardiology. He also needed treatment by audiologists, specialists at a low-vision clinic, and physical, occupational, and speech therapists. There was no 'team leader' to coordinate this

confusing array of specialists. I spent several hours each week during my residency at doctors' appointments for Christopher. I concluded that the care and management of a patient with a chronic disease should never be more stressful to the family than the disease itself."

This experience caring for Christopher profoundly shaped the course of Dr. Jackson's career and her vision for providing comprehensive neurologic care for others.

"As a result," she says, "I became committed to creating a community of competent health professionals that could ease the stress associated with dealing with a progressive degenerative disease. If it takes a village to raise a child, it also takes a team of health care providers to treat patients with a chronic neurologic disease. The care has to be consistent and convenient. There needs to be support for the caregivers as well as the patient. The patient needs to be seen as an individual, not as a diagnosis. Families and patients must be given hope—not only for the possibility of a cure, but hope that the burden of their disease will be minimized as much as possible. Patients must know that their wishes will be respected, their symptoms will be treated, and that they will never be abandoned."

Christopher died 11 years ago, but his legacy lives on in the work that Dr.

Jackson and her team perform each day. They are making the lives of patients with neuromuscular diseases and their families better by providing comprehensive, coordinated care. If you have had a chronic neurologic disease as a child, or are a family member of a child with a chronic disease, please tell us about your experience. It might help make life better for someone else.

Take good care,

Robin L. Brey, M.D.
Editor-in-Chief



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