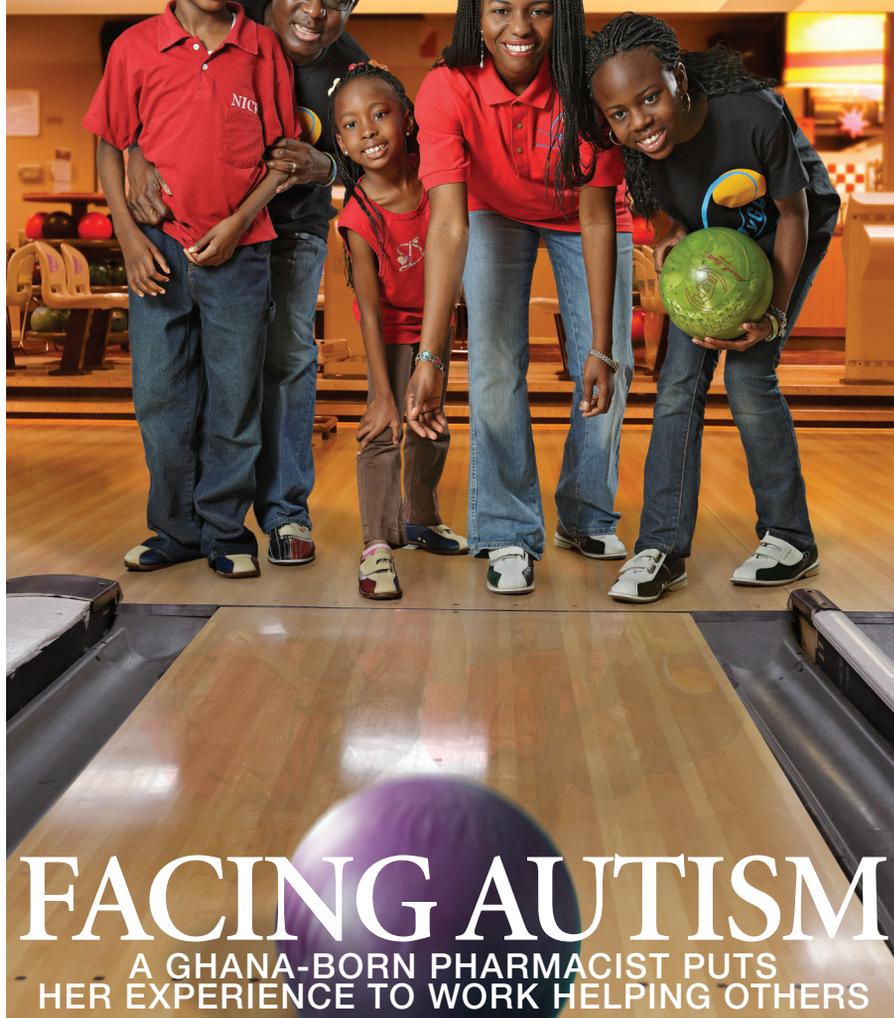


The Kumapleys, from left: Nicholas, Robert, Delali, Genevieve and Sena



# FACING AUTISM

## A GHANA-BORN PHARMACIST PUTS HER EXPERIENCE TO WORK HELPING OTHERS

**GENEVIEVE KUMAPLEY DIDN'T** know what to think when her 15-month-old, Nicholas, started acting strangely.

"He seemed not as alert," she says. "He stopped responding to his name, and he lost language."

That was a decade ago, before many of the media reports that have made developmental problems at least vaguely familiar to most of us. Though Kumapley was a doctor of pharmacy and an immigrant who had crossed the ocean from her native Ghana at age 14, she wasn't ready for the new world she entered when Nicholas was diagnosed with autism. "I had never heard of autism," admits Kumapley, now 39 and a Saint Peter's University Hospital pharmacist.

Autism is a developmental disorder—often called a "spectrum" of disorders—characterized by varying

degrees of self-absorption, inability to communicate and repetitive behaviors. In those days, besides dealing with an often unresponsive and difficult son, Kumapley faced painful misunderstanding, ignorance and rejection in others.

"There was a lot of denial in our community and a lot of myths, and people were not quick to talk about it," she recalls. Some people believed that a child with autism was demonically possessed. Others thought autism had something to do with race or gender or religion, and still others held the mother responsible. For almost all, autism was a source of shame, something to be hidden.

Kumapley and her husband, Robert, an engineer, found that their extended family avoided Nicholas and did not want to acknowledge his disability. "They thought it was something that

we'd done wrong or that Nicholas had done wrong," she says.

Like many autistic kids, Nicholas (now 11) had accompanying physical problems—chronic colds and gastrointestinal ailments—and the couple also had two typically developing kids to care for: daughters Sena, now 13, and Delali, now 7. It was a struggle to find the information they needed about insurance, education and medical treatment and to adapt the family's routines to Nicholas's care. Their marriage began to suffer.

But experts say one way to help yourself is to help others, and doing just that has changed Kumapley's life. Five years ago she started a nonprofit foundation called MyGOAL Inc., which offers support to parents of children with autism, especially those who have to overcome misunderstanding, as she did, to help their children get proper and respectful care. The name is an acronym: My Gateway to Overcoming Autism in Life.

Today, MyGOAL raises money through various fundraising events—bowl-a-thons, 5K races and music and dance concerts—which it gives out in small grants to families to ensure that they have the resources they need to learn about autism and to care for an autistic child. "We help break the disorder down to the level that people can understand, and ensure that language and financial issues don't stop them from getting what they need," Kumapley explains. The group holds meetings, conferences and support-group sessions. Through it the Kumapleys have worked with autism families both here and overseas—and found new direction themselves.

Genevieve Kumapley has come a long way from the day Nicholas was diagnosed. "It occurred to us that if, as a pharmacist and an engineer, we couldn't deal with all this, how would someone in a more difficult situation handle it?" she says, explaining the group she founded and now leads.

"There are many organizations that focus on the kids," she says. "We focus on parents and families." —D.L.

TO LEARN MORE ABOUT AUTISM SERVICES AT THE CHILDREN'S HOSPITAL AT SAINT PETER'S UNIVERSITY HOSPITAL, PLEASE CALL BARBIE ZIMMERMAN-BIER, M.D., 732.339.7045, OR VISIT SAINTPETERSHCS.COM/SPCHILDRENSHOSPITAL. TO FIND OUT MORE ABOUT MYGOAL, VISIT MYGOALAUTISM.ORG.



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