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NEWSRELEASE

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NEW RESOURCE AVAILABLE FOR PARENTS OF CHILDREN DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER

New Jersey Medical School autism experts help parents navigate the maze of medical services

NEWARK, NJ (November 10, 2014) – Navigating through the maze of health and medical services can be challenging for parents of children who have been diagnosed with autism spectrum disorders (ASDs). A new resource is now available for caregivers, health professionals and, especially, parents. A pediatric neurologist and pediatrician/geneticist at Rutgers New Jersey Medical School recognized a need for a comprehensive guide to help parents obtain quality medical care for each stage of their child's development.

As a result, "Navigating the Medical Maze with a Child with Autism Spectrum Disorder: A Practical Guide for Parents" (September 2014, ISBN: 978-1-84905-971-8) was published to show parents how to play an effective and active role in their child's medical care from diagnosis through early adulthood. According to Sue X. Ming, MD, PhD, professor of Neuroscience and Neurology, and Beth A. Pletcher, MD, associate professor of Pediatrics and Medicine, the guide includes lay descriptions of developmental and medical conditions, explanations about common diagnostic tests, and tips on managing day-to-day medical and behavioral challenges.

Ming said, "According to the Centers for Disease Control and Prevention, the rate of autism in 8-year old New Jersey children is 1 out of 45. In contrast, nationally, the statistic is 1 in 68 children. Boys are more likely than girls to be diagnosed with an ASD. The CDC reported an estimated cost of caring for children with ASDs to be more than \$9 billion three years ago."

Somerset County resident Brian Kerwin understands the problem firsthand. He remembers seeing his son bent over in severe gastrointestinal pain. That was before Connor was diagnosed at age two. He is now 23-years old. Although Connor does not communicate verbally, he lives with his loving parents and has three supportive brothers.

"Connor is always in pain; sometimes he feels good enough that he forgets about it," said Kerwin. While flipping through the guide, Kerwin sees chapters that would have helped when Connor was first diagnosed and other topics that are useful now: oral and dental exams; allergies and immunology; gastrointestinal disorders. "When I look at the chapters, I recognize that there's no longer the denial of medical comorbidities that we experienced," Kerwin said, whose family established a 'Medically Fragile Autistic' Facebook page to advocate for children with autism.

Instead of communicating verbally, Kevin Clinton expresses himself through body language. Long before Kevin was diagnosed at age 10, his mother, Cassandra Clinton served as his voice. She continues to be her 26-year old son's biggest advocate and receives tremendous support from her daughters, ages 29 and 23.

This Jersey City resident and mother of three constantly searches for services that enhance Kevin's quality of life. Clinton believes this guide would have been helpful when she was seeking a diagnosis for her son. "I'm glad Dr. Ming and Dr. Pletcher have addressed the parent's voice in this guide," said Clinton. What's her advice to parents? "Be your child's biggest advocate. If you believe something is wrong. Trust your gut and seek services to address his or her special needs. Don't give up."

Another parent Catherine Wersinger, of Monmouth County, also could have used the guide years ago when her 2-year old son was diagnosed with ASD. Now, the 15-year old is a high functioning honor roll student, a high school wrestler and football player. "This kind of reference could only help parents of a newly diagnosed child as well as teenagers and young adults. It would be great for physicians to have this guide in their waiting rooms. For parents of a newly diagnosed child, it would be a Godsend."

Ming and Pletcher's significant clinical experience in caring for children with ASDs and interacting with their parents put these health professionals on a quest to make life easier for caregivers. They gathered practical descriptions and explanations of autism and related conditions, diagnostic tests, conventional and complementary therapies, and more.

Pletcher said, "The guide is meant for parents who want more depth beyond the basic information. We want to help parents and caregivers to be more informed during visits with medical professionals. We want them to have efficient and productive medical encounters. In addition to a glossary of terms, each chapter has takeaway points and questions to ask doctors. The guide is intended to help parents work collaboratively with multiple health and medical specialties, from birth through young adulthood."

Faculty members from various institutions, including the Rutgers School of Dental Medicine, have contributed to the guide on oral health care, environmental, puberty and neurologic issues. Ming and Pletcher are optimistic about the future. Ming said, "While nothing totally replaces a visit with a health professional, parents need strategies for navigating through the maze of health care services. Having details and pointed questions may help reduce their anxieties. Autism can be improved by treating the disorder and associated conditions."

Celebrating its 60th anniversary, **Rutgers New Jersey Medical School** was founded in 1954 and is the oldest school of medicine in the state. Today it is part of Rutgers, The State University of New Jersey and graduates approximately 170 physicians a year. In addition to providing the MD degree, the school offers MD/PhD, MD/MPH and MD/MBA degrees through collaborations with other institutions of higher education. Dedicated to excellence in education, research, clinical care and community outreach, the medical school comprises 22 academic departments and works with several healthcare partners, including its principal teaching hospital, The University Hospital. Its faculty consists of numerous world-renowned scientists and many of the region's "top doctors." Home to the nation's oldest student-run clinic, New Jersey Medical School hosts more than 50 centers and institutes, including the Public Health Research Institute

Center, the Global Tuberculosis Institute and the Neurological Institute of New Jersey. For more information please visit: njms.rutgers.edu.

