Many pediatricians uncomfortable providing care to kids with genetic conditions

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Many primary care pediatricians say they feel uncomfortable providing health care to patients with genetic disorders. Also, many do not consistently discuss all risks and benefits of genetic tests with patients, according to research published today in the *American Journal of Medical Genetics*.

Investigators from the University of Michigan's C.S. Mott Children's Hospital and The Children's Hospital at Montefiore (CHAM) conducted a national survey of 88 physicians who are part of the American Academy of Pediatrics Quality Improvement Innovation Networks, assessing their comfort level ordering genetic tests for their pediatric patients, their attitudes toward genetic medical care and their choices regarding taking family histories. The majority of those physicians reported ordering few genetic tests (three or less times) per year, excluding newborn screening which is federally mandated for all newborns; few (13 percent) strongly agreed that they discussed the potential risks, benefits, and limitations of genetic tests with all their patients and only half felt competent in providing healthcare to patients with genetic disorders.

"While genetics has historically been viewed as a discipline focused on rare conditions, recent genomic advances have highlighted that genetics has a role in common conditions encountered in primary care medicine," said Beth Tarini, M.D., M.S., F.A.A.P., senior author, assistant professor of pediatrics, Child Health Evaluation & Research (CHEAR) Unit, Division of General Pediatrics, University of Michigan and co-medical

director of the Genetics in Primary Care Institute (GPCI), a project of the American Academy of Pediatrics. "Unfortunately, most PCPs have received insufficient education and training about genetics, which has left them uncertain about their role in providing genetics related care."

The study found that 100% of study participants stated that taking a family history is important, but less than one-third stated that they gather a minimum of a three-generation family history, a basic component of a genetic medical evaluation. Previous studies have shown that using family history and genetic information greatly improved outcomes for patients so researchers encourage patients to know their family history and share this with their providers in order to optimize their health care.

"PCPs play an integral role in caring for children with genetic conditions and it is vital that they feel comfortable identifying issues and providing comprehensive care to suit their patients' unique needs," said Michael L. Rinke, M.D., Ph.D., lead author and assistant medical director for quality, CHAM, and assistant professor of pediatrics at Albert Einstein College of Medicine of Yeshiva University. "Thousands of children in the U.S. are diagnosed with genetic disorders annually and in order to optimize outcomes for these patients' early identification and medical intervention is essential."

The researchers say that robust education, increased access to resources, improved electronic health records systems to document family histories and rigorous quality improvement efforts are key to enhancing integration of genetic medicine into routine primary preventative care.

Tarini says that the national Genetics in Primary Care Institute Quality Improvement Project hopes to identify effective strategies so that physicians who are at the forefront of diagnosing and managing patients with genetic disorders feel confident and competent in their abilities to provide care for these patients.

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