Survey: Most pediatricians take family history, fewer order genetic tests

from the AAP Department of Research

Primary care pediatricians routinely collect family health histories, and most have identified at least one patient as being at risk for a genetic-related disorder in the past year, according to new research from the AAP Periodic Surveys of Fellows (Saul RA, et al. J Community Genet. 2017;8:109-115, doi: 10.1007/s12687-016-0291-3). Fewer pediatricians, however, order genetic tests themselves.

Ninety-seven percent of pediatricians reported collecting a family health history with new patients usually or all the time, and 91% reported that it is the role of primary care pediatrics to collect family history information.

Most pediatricians (90%) also reported being confident in their ability to discuss the results of a family history with parents. The majority of pediatricians (51%) reported that they collect the family history using a standardized disease checklist. They commonly collect data on first-degree (99%) (child/sibling/parents) and second-degree (94%) (aunts/uncles/nieces/nephews/grandparents) relatives, but not on third-degree (27%) (first cousins) relatives.

In the past year, 75% of primary care pediatricians reported having identified at least one patient as being at-risk for a genetic-related disorder, with an average number of six identified patients. Half of pediatricians reported referring these patients to geneticists or other specialists rather than ordering genetic tests themselves. Common barriers that pediatricians reported to ordering genetic testing included lack of training on interpreting the results (60%), lack of care management guidelines (57%) and lack of training on selecting appropriate genetic tests (53%) (see figure). Just under half also reported inadequate time during a typical office visit to interpret results.

Three-fourths of pediatricians reported that they would be interested in continuing medical education programs on genetics in primary care.

RESOURCES

• 2013 supplement in Pediatrics “Genetics and Genomic Literacy in Pediatric Primary Care,” which includes an article on family health history-taking, http://pediatrics.aappublications.org/content/132/Supplement_3.
• Pedialink course Dive into the Gene Pool, https://shop.aap.org/dive-into-the-gene-pool/
• For more information on the Periodic Survey of Fellows, visit http://www2.aap.org/research/periodic_survey.htm or contact Blake Sisk, in the AAP Division of Health Services Research, at 847-434-7630 or bsisk@aap.org.

Percent of primary care pediatricians reporting barriers to genetic testing or evaluation, 2014

<table>
<thead>
<tr>
<th>Barriers</th>
<th>% of pediatricians</th>
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<tbody>
<tr>
<td>Lack of training on genetic interpretation</td>
<td>60%</td>
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<tr>
<td>Lack of care management guidelines</td>
<td>57%</td>
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<tr>
<td>Lack of training in identifying genetic risks and choosing appropriate tests</td>
<td>53%</td>
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<tr>
<td>Inadequate time during typical visit to interpret genetic tests</td>
<td>49%</td>
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<td>Inadequate insurance reimbursement for genetic tests</td>
<td>31%</td>
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AAP Periodic Survey #87


Storms test pediatric hospitals’ disaster preparedness efforts

As record-setting floods and hurricane-force winds wreaked havoc on hospitals, homes and other buildings in the south, pediatric providers like Brian Rissmiller, M.D., FAAP (right), coped with professional and personal demands. The day after his Houston home and neighborhood flooded, Dr. Rissmiller, a critical care physician at Texas Children’s Hospital (TCH), retrieved a few of his family’s belongings during a period of relative calm. Along with his wife and three young daughters, Dr. Rissmiller took shelter at the home of a neighbor with a second story. He also was to be part of an initial “ride-out” team at TCH’s Medical Center campus but was sent home early due to adequate coverage in his unit. TCH had elaborate staffing plans to meet demands during a rapidly changing situation. The hospital also played a critical role in arranging emergency transport for young children across the region with complex medical needs. Find more coverage in the November issue of AAP News.