

Checklist helps parents, physicians track services needed by children with Down syndrome

by **Alyson Sulaski Wyckoff** • Associate Editor

A new consumer-friendly checklist can help families keep tabs on the services and screenings recommended for children with Down syndrome at every stage, from prenatal to young adult.

The 11-page checklist, *Health Care Information for Families of Children with Down Syndrome*, reflects updated recommendations in the AAP clinical report, *Health Supervision for Children with Down Syndrome* (*Pediatrics*. 2011;128:393-406). It also marks what is thought to be the first consumer translation of an AAP report or policy statement (see resources).



Dr. Bull

The clinical report reflected several key changes in the guidance, according to Marilyn J. Bull, M.D., FAAP, who initiated the checklist and was lead author of the clinical report from the AAP Committee on Genetics.

Among the changes is a greater emphasis on communicating with families at the prenatal and infant stages; using the growth charts of the National Center for Health Statistics or World Health Organization until new research quality standards are developed; and noting the critical importance of proper evaluation for atlantoaxial instability (see August 2011 *AAP News* article, “AAP Updates Guidance on Caring for Children with Down Syndrome,” <http://aapnews.aappublications.org/content/early/2011/07/25/aapnews.20110725-3.full>).

Pediatricians typically see only a handful of patients with Down syndrome. Therefore, it’s helpful to have access to a checklist of all the medical and developmental issues that need monitoring, said Dr. Bull, chair of AAP District V and AAP board member.

“We need to get this information to the point of care and primary care physician,” she said.

The working group for the checklist included parents of children

with Down syndrome as well as representatives of Down syndrome organizations. A writing panel converted the guidance in the clinical report to language that is easy to understand.

“It’s extremely important that we enable physicians and families to access the best practices from the report,” said Dr. Bull. She said she has received more feedback on the checklist — especially from international sources “from Singapore to Albania” — than on any other AAP document she has been involved in writing.

Many overseas physicians have sought permission to translate the checklist; a Spanish translation is planned and will be posted on Healthy Children en Español.

Ideally, physicians should place a copy of the checklist in a patient’s file or scan it into the electronic health record, said Dr. Bull. Families should carry the list to their child’s pediatrician and subspecialist appointments.

“They can tell the doctor, ‘This is what the American Academy of Pediatrics says is best for my child.’”

RESOURCES

- Download the checklist, *Health Care Information for Families of Children with Down Syndrome*, at <http://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx>.
- Read the 2011 clinical report, *Health Supervision for Children with Down Syndrome* at <http://pediatrics.aappublications.org/content/128/2/393.full.pdf+html>.
- Find the Spanish version of the clinical report at <http://pediatrics.aappublications.org/content/128/2/393/suppl/DC1>.