

# Is There a Special Growth Chart for Children with Down Syndrome?



**D**OWN SYNDROME (ALSO referred to as trisomy 21) is caused by the presence of an extra copy of chromosome number 21. Down syndrome remains the most common chromosomal condition diagnosed in the United States. Each year, about 6,000 babies born in the United States have Down syndrome and that equates to approximately 1 out of every 700 babies born.<sup>1</sup> Infants and children with Down syndrome are at increased risk for health-related issues and need additional services beyond that required by children generally.<sup>2</sup> It is imperative that the registered dietitian nutritionist does a comprehensive nutritional assessment to provide appropriate individualized medical nutrition therapy.

A major aspect of the ongoing assessment is to monitor the child's or infant's growth pattern. Early identification of a growth problem is important because timely interventions may positively affect the child's general health and functional abilities as well as supporting growth.<sup>3</sup> Growth charts are the tools generally used to evaluate anthropometric measurements recording the weight and length or height for children and the head circumference for infants. In 2010, the Centers for Disease Control and Prevention (CDC) recommended that the World Health Organization (WHO) growth standards be used to monitor growth for infants and children ages 0 to 2 years of age.<sup>4</sup> The CDC growth charts are used for children and adolescents between 2 and 20 years of

age. The growth charts and instructions on how to use them are available on the CDC website.<sup>5</sup>

A number of specialized growth charts have been developed for some specific medical conditions, certain genetic syndromes, and for premature infants. It has been noted that individuals with Down syndrome may grow more slowly and can be shorter than their typical developing peers,<sup>6</sup> and special growth charts have been developed for this specific syndrome. Since these special growth charts were developed, concerns have been raised regarding their usefulness. The issues raised include: 1) the charts were developed from a very small sample size of patients and did not reflect racial, ethnic, or geographical diversity, and 2) in addition, the nutritional status of the children in the sample was not assessed, so it is difficult to know whether or not the data represent a well-nourished group of children or reflect problems associated with nutritional status.<sup>3,6</sup>

In 2011 the American Academy of Pediatrics recommended using the WHO and CDC standard growth charts for patients with Down syndrome.<sup>2-4,6,7</sup> However, in some recently published literature and on the Internet there are still references made to the Down syndrome-specific growth charts.

It is the expectation that each child grow at his or her own potential, even if it is below the normal growth curves using the WHO and CDC growth charts. It is acceptable for a child to grow at slower rates if they are consistently tracking along a satisfactory curve as determined by the clinician.<sup>3</sup> A study funded by CDC was recently published in *Pediatrics* and provides new growth charts for children with Down syndrome. Currently, access to these charts is only available on the American Academy of Pediatrics website.<sup>8</sup> The registered dietitian nutritionist should

monitor the growth curves and use this information in the assessment of the infant or child.<sup>2</sup>

## References

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5. Center for Disease Control and Prevention. Growth charts. <http://www.cdc.gov/growthcharts>. Accessed October 20, 2015.
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## Additional Academy Resource:

Standards of Practice Academy of Nutrition and Dietetics: Standards of Practice and Standards of Professional Performance for Registered Dietitians (Competent, Proficient, and Expert) in Intellectual and Developmental Disabilities. *J Acad Nutr Diet*. 2012;112(9):1454-1464.e35. [http://www.andjrn.org/article/S2212-2672\(12\)01188-4/abstract](http://www.andjrn.org/article/S2212-2672(12)01188-4/abstract).

## Additional Resources:

CDC—Down syndrome [www.cdc.gov/features/down-syndrome/index.html](http://www.cdc.gov/features/down-syndrome/index.html)

National Down Syndrome Society [www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome](http://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome)

This article was written by **Wendy Marcason, RDN**, of the Academy of Nutrition and Dietetics' Knowledge Center Team, Chicago, IL. Academy members can contact the Knowledge Center by sending an e-mail to [knowledge@eatright.org](mailto:knowledge@eatright.org).

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