

Nutrition researchers to develop new growth charts for children with Down syndrome

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Parents and doctors have known for a long time that children with Down syndrome tend to grow more slowly and are considerably shorter than most other children. But pediatricians needing to record growth milestones at regular office visits have an outdated set of growth charts based on data collected more than 25 years ago. Since that time, there have been major advances in the medical care of children with Down syndrome. In addition, the demographics of the general U.S. population have changed, and children are taller, but also more overweight.

Now researchers at The Children's Hospital of Philadelphia will be measuring [children](#) with [Down syndrome](#) from birth to age 21 to develop updated growth charts. A four-year, \$1.2 million grant from the Centers for Disease Control and Prevention (CDC) is supporting this effort, which brings together experts from the Hospital in growth and nutrition, Down syndrome (also called trisomy 21), and general pediatrics.

One of the most common birth defects, Down syndrome occurs in approximately one in 700 births. The National Down Syndrome Society estimates that there are more than 400,000 people living with Down syndrome in the U.S. It is a genetic disorder, usually resulting from having three copies of [chromosome 21](#), instead of the usual two copies.

Because the extra chromosome generally occurs in every cell in the body, it can affect many different systems, causing [congenital heart disease](#), recurrent ear and sinus infections, hearing loss, thyroid disorders, visual impairment, and gastrointestinal disorders. Neurological

effects include developmental disability, which can range from low-average abilities to severe intellectual impairment.

"The past 20 years have seen significant improvements in the care of children with Down syndrome, accompanied by longer life expectancy," said the grant's principal investigator, Babette S. Zemel, Ph.D., director of the Nutrition and Growth Laboratory at The Children's Hospital of Philadelphia. "We believe that children with Down syndrome are growing better now than they were 20 years ago. We also want to look at how they are growing throughout childhood, from infancy to young adulthood, at how body mass index changes across time, and how that relates to body fat composition.

"If we can better understand the growth patterns and the rates of other illnesses that co-occur with Down syndrome, researchers may be better able to plan treatment and design preventive health programs," added Zemel. "The CDC has recognized updated growth charts as an important tool for people providing health care to children with Down syndrome." In its grant guidelines, the CDC states that new growth charts produced from the study will be broadly distributed free of charge.

Under the grant, Zemel and colleagues will recruit approximately 600 children with Down syndrome, from birth to 20 years old, from Southeastern Pennsylvania, New Jersey and Delaware. In regularly scheduled follow-up visits, the researchers will measure the patients' growth and body dimensions and collect data about their health, dietary patterns and physical activities.

"In addition to developing more representative growth charts, we also expect to better understand what factors may contribute to growth-related problems in children with Down syndrome," added Zemel. Another important goal is to develop a screening tool for identifying children at risk for overweight and obesity, which are common concerns

for adolescents and young adults with Down syndrome.

Provided by Children's Hospital of Philadelphia

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