BIOMARIN®

Stature | Weight for Age | Weight for Height | Head Circumference

Achondroplasia Growth Curves **CLARITY Study**

Hoover-Fong *et al.*
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Growth in achondroplasia including stature, weight, weight-for-height and head circumference from CLARITY: achondroplasia natural history study—a multi-center retrospective cohort study of achondroplasia in the US

Julie E. Hoover-Fong[1*], Kerry J. Schulze[1,2], Adekemi Y. Alade[1,2], Michael B. Bober[3], Ethan Gough[1,2], S. Shahrukh Hashmi[4], Jacqueline T. Hecht[4,5], Janet M. Legare[6], Mary Ellen Little[3], Peggy Modaff[6], Richard M. Pauli[6], David F. Rodriguez-Buritica[4], Maria E. Serna[4], Cory Smid[6,7], Chengxin Liu[1] and John McGready[1,2]

Abstract

Background: Achondroplasia is the most common genetic skeletal disorder causing disproportionate short stature/dwarfism. Common additional features include spinal stenosis, midface retrusion, macrocephaly and a generalized spondylometaphyseal dysplasia which manifest as spinal cord compression, sleep disordered breathing, delayed motor skill acquisition and genu varus with musculoskeletal pain. To better understand the interactions and health outcomes of these potential complications, we embarked on a multi-center, natural history study entitled CLARITY (achondroplasia natural history study). One of the CLARITY objectives was to develop growth curves (length/height, weight, head circumference, weight-for-height) and corresponding reference tables of mean and standard deviations at 1 month increments from birth through 18 years for clinical use and research for achondroplasia patients.

Methods: All available retrospective anthropometry data including length/height, weight and head circumference from achondroplasia patients were collected at 4 US skeletal dysplasia centers (Johns Hopkins University, Al DuPont Hospital for Children, McGovern Medical School University of Texas Health, University of Wisconsin School of Medicine and Public Health). Weight-for-age values beyond 3 SD above the mean were excluded from the weight-for-height and weight-for-age curves to create a stricter tool for weight assessment in this population.

Results: Over 37,000 length/height, weight and head circumference measures from 1374 patients with achondroplasia from birth through 75 years of age were compiled in a REDCap database. Stature and weight data from birth

*Correspondence: jhoover2@jhmi.edu
[1] Greenberg Center for Skeletal Dysplasias, McKusick-Nathans Department of Genetic Medicine, Johns Hopkins University, 733 N. Broadway Suite 579, Baltimore, MD 21205, USA
Full list of author information is available at the end of the article

INTRODUCTION

Achondroplasia-specific growth curves are essential for clinical care of growing infants and children with achondroplasia. Therefore, one objective of CLARITY, a multicenter retrospective cohort of achondroplasia in the US, was to develop updated growth curves and corresponding reference tables of mean and standard deviations at 1 month increments from birth through 18 years for clinical use and research for achondroplasia patients.

CLARITY researchers collected what is thought to be the largest dataset of anthropometric measures in patients with achondroplasia, including 1374 subjects and totaling over 37,000 data points. Anthropometry data were consolidated from all available patient records which provided linked medical history (eg, gestational age), surgical history (eg, limb lengthening, cervicomedullary decompression) and medical treatments (eg, growth hormone therapy).

Achondroplasia Growth Curves | CLARITY Study

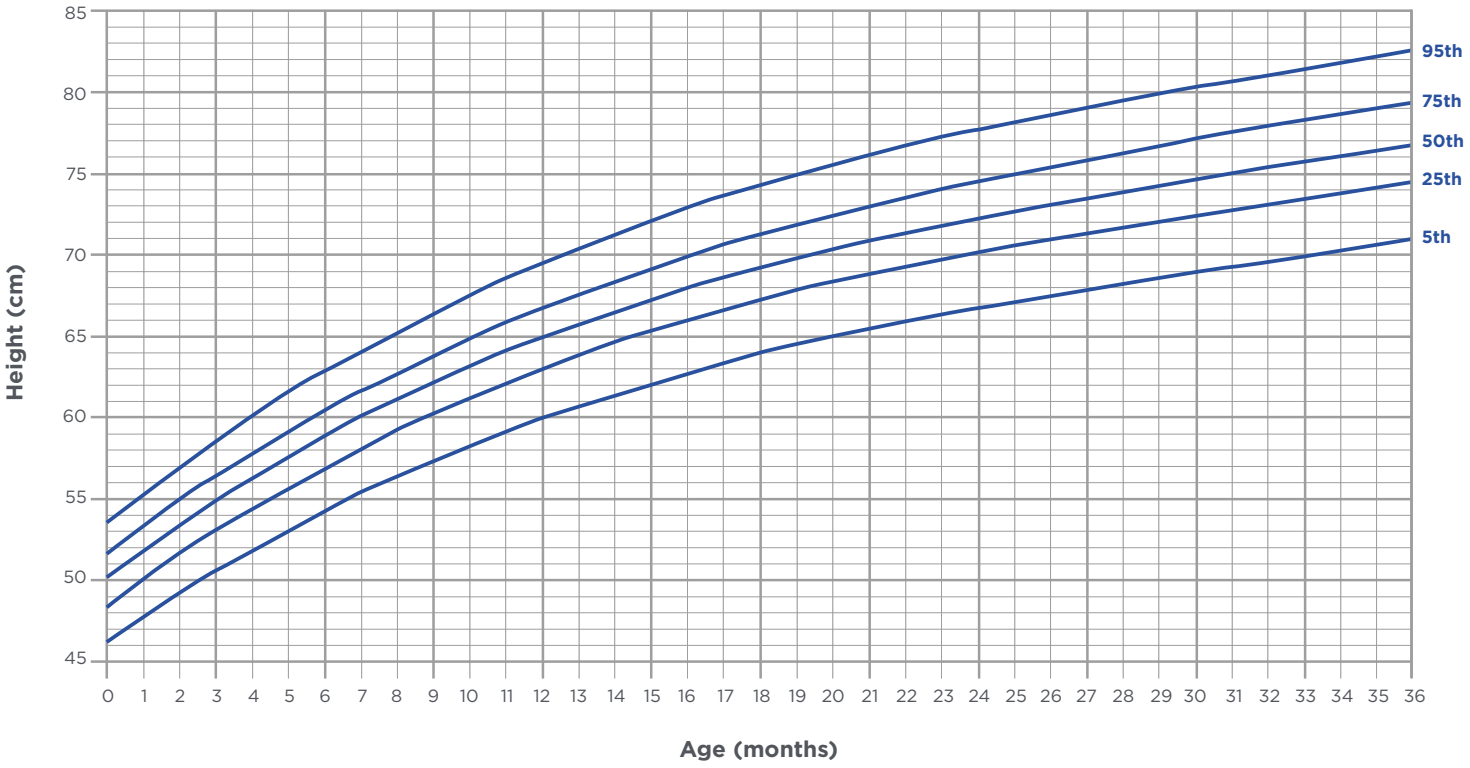
Stature | Weight for Age | Weight for Height | Head Circumference

Length for Age
Males
Birth to 36 Months

Height for Age
Males
2 to 18 Years

Length for Age
Females
Birth to 36 Months

Height for Age
Females
2 to 18 Years



Derived from 3024 data points from 544 subjects.

Achondroplasia Growth Curves | CLARITY Study

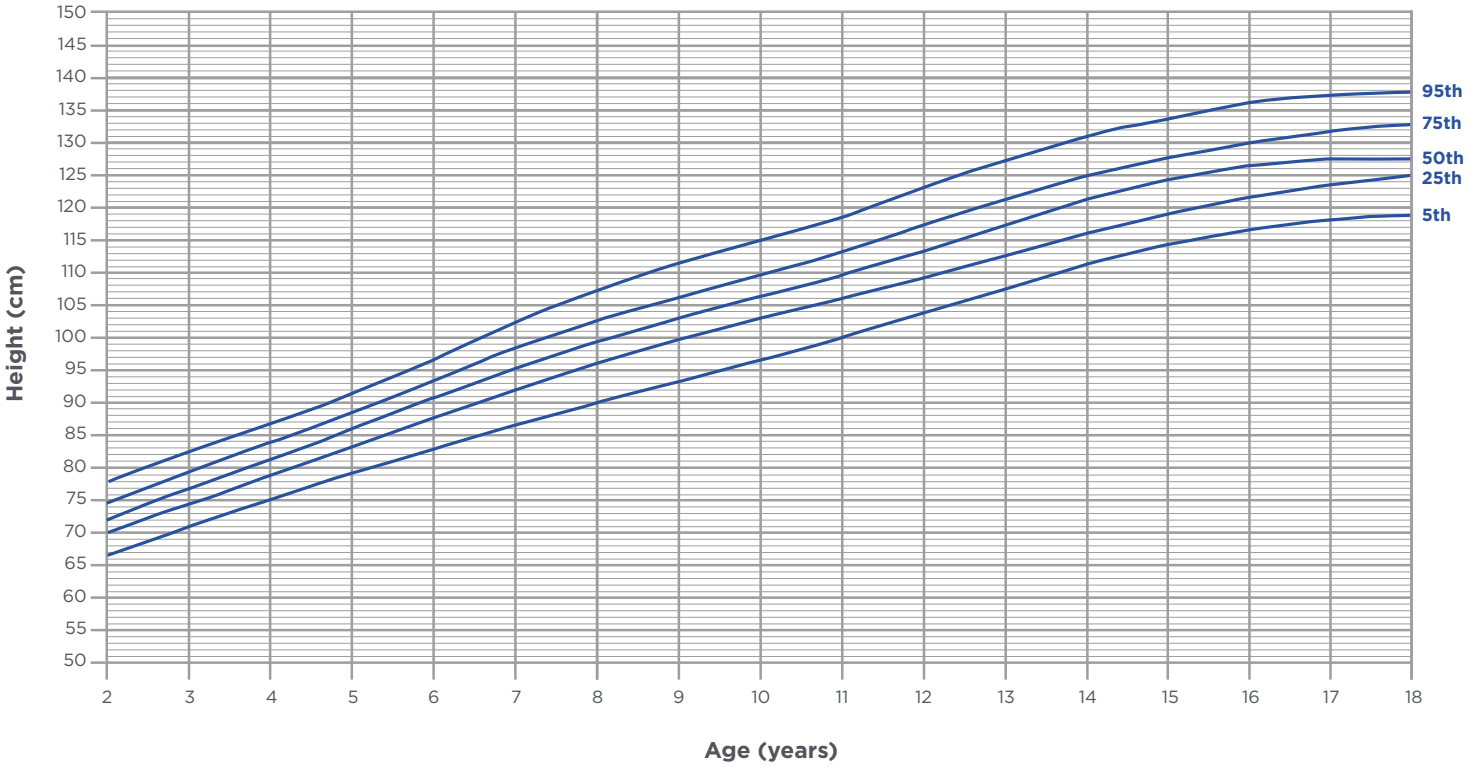
Stature | Weight for Age | Weight for Height | Head Circumference

Length for Age
Males
Birth to 36 Months

Height for Age
Males
2 to 18 Years

Length for Age
Females
Birth to 36 Months

Height for Age
Females
2 to 18 Years



Derived from 4011 data points from 549 subjects.

Adapted from: Hoover-Fong JE et al. *Orphanet J Rare Dis.* 2021;16:522.

Achondroplasia Growth Curves | CLARITY Study

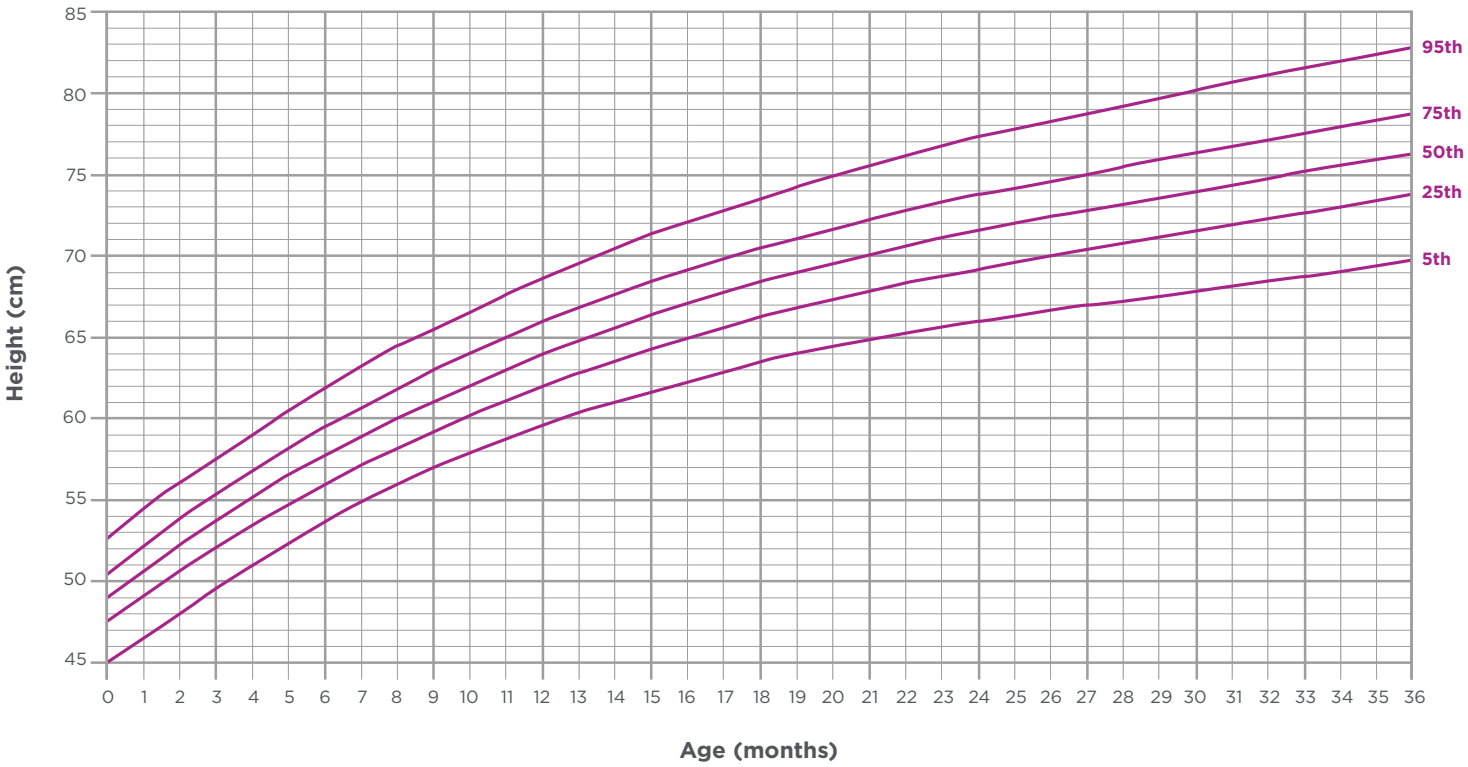
Stature | Weight for Age | Weight for Height | Head Circumference

Length for Age
Males
Birth to 36 Months

Height for Age
Males
2 to 18 Years

Length for Age
Females
Birth to 36 Months

Height for Age
Females
2 to 18 Years



Derived from 2700 data points from 489 subjects.

Achondroplasia Growth Curves | CLARITY Study

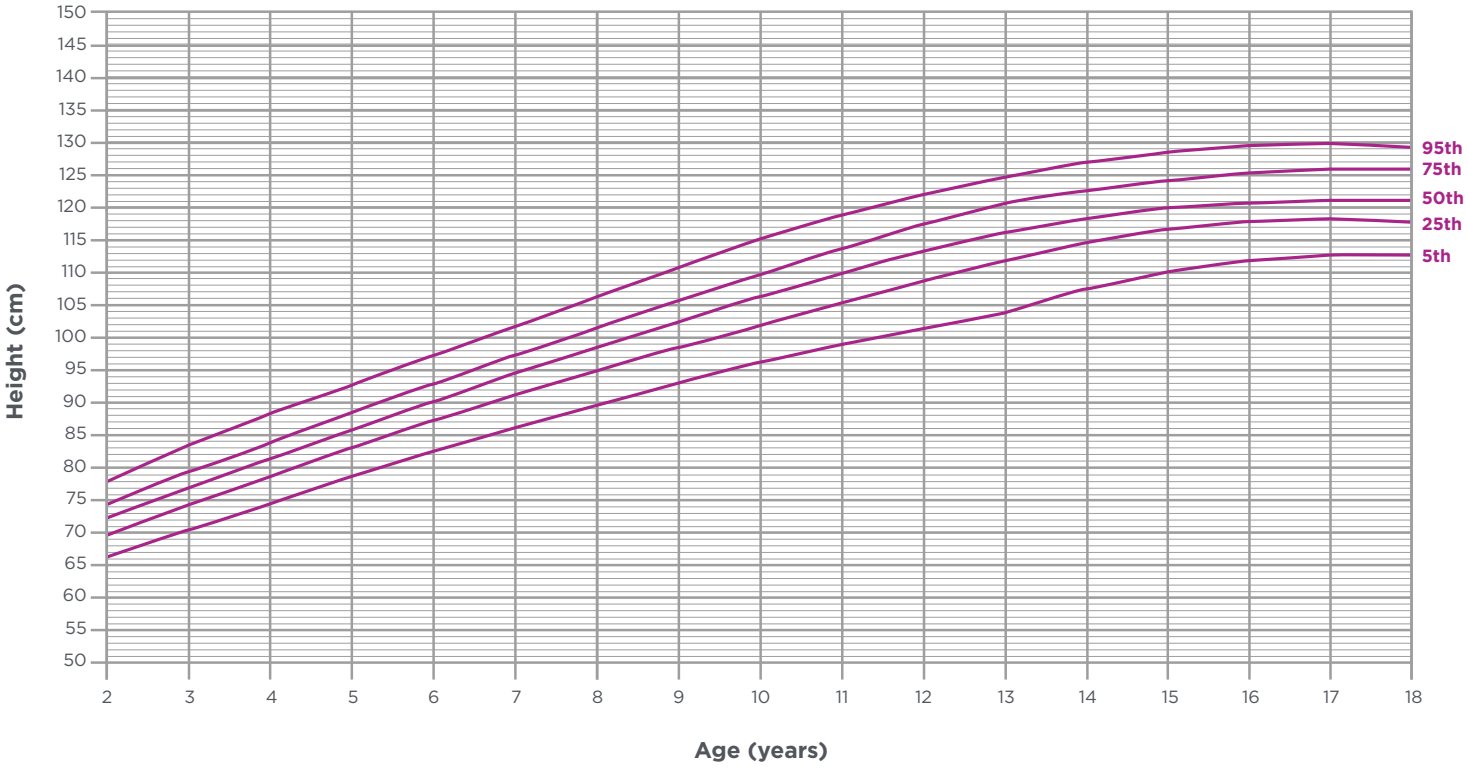
Stature | Weight for Age | Weight for Height | Head Circumference

Length for Age
Males
Birth to 36 Months

Height for Age
Males
2 to 18 Years

Length for Age
Females
Birth to 36 Months

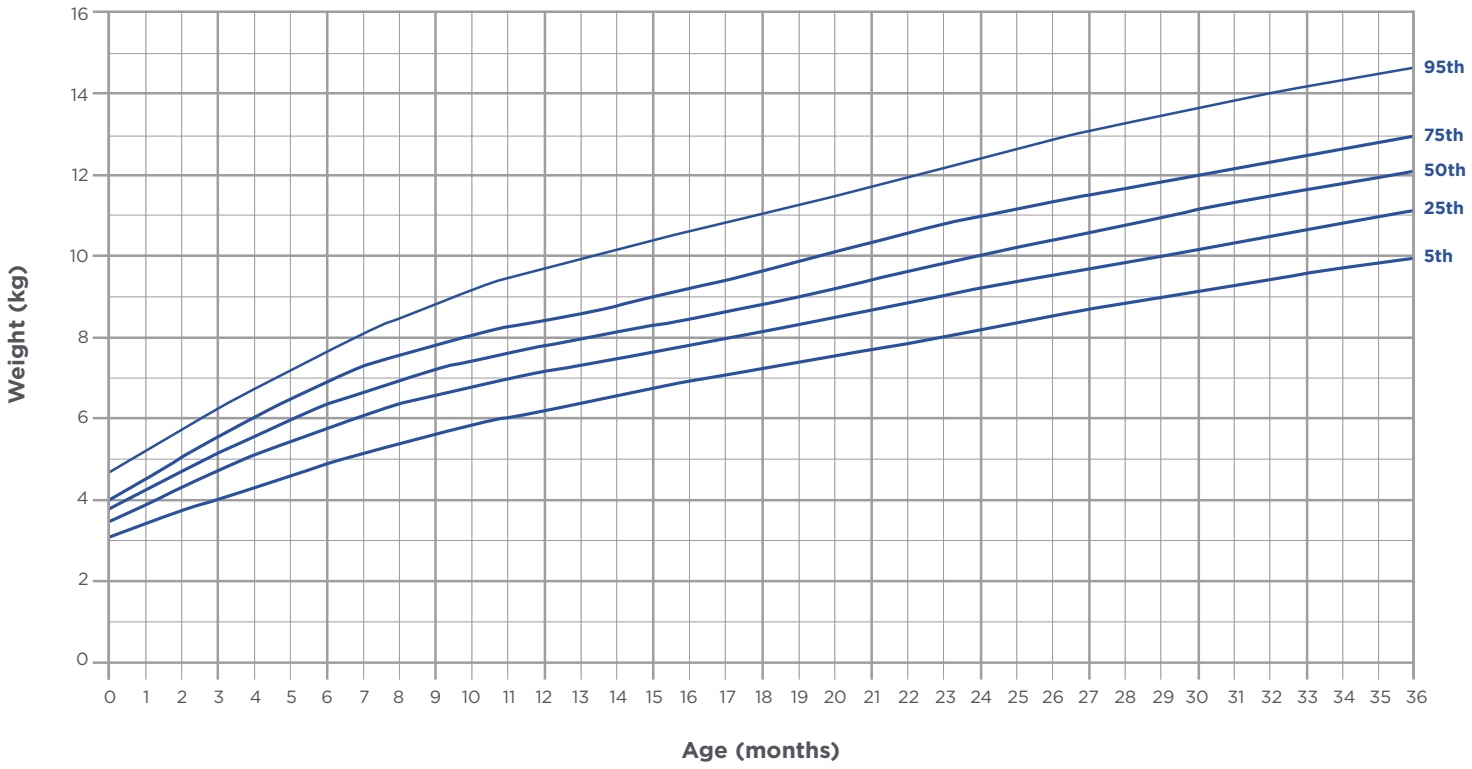
Height for Age
Females
2 to 18 Years



Derived from 3703 data points from 502 subjects.

Adapted from: Hoover-Fong JE et al. *Orphanet J Rare Dis.* 2021;16:522.

Weight for Age
Males
Birth to 36 Months



Derived from 3585 data points from 549 subjects.

Weight for Age
Males
2 to 18 Years

Weight for Age
Females
Birth to 36 Months

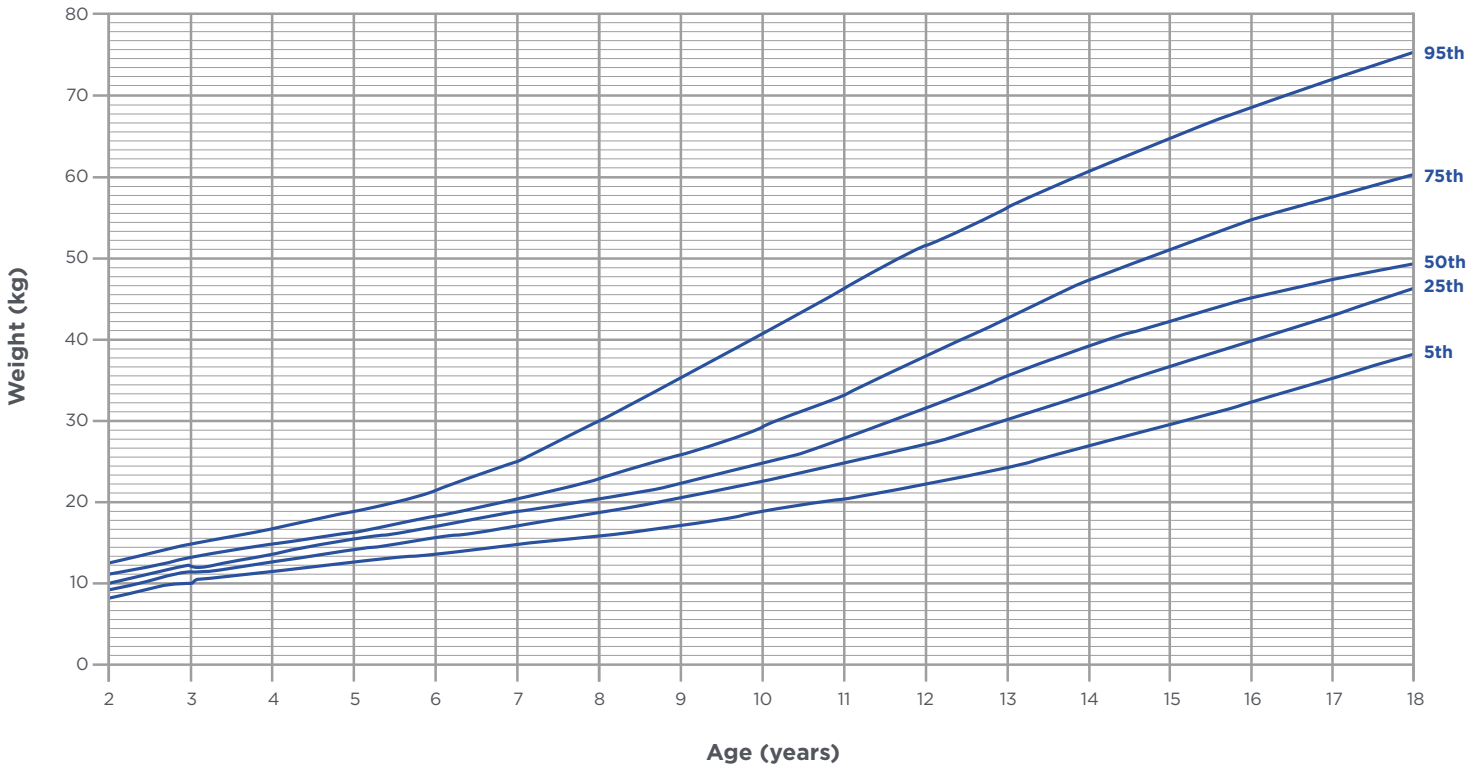
Weight for Age
Females
2 to 18 Years

Weight for Age
Males
Birth to 36 Months

Weight for Age
Males
2 to 18 Years

Weight for Age
Females
Birth to 36 Months

Weight for Age
Females
2 to 18 Years



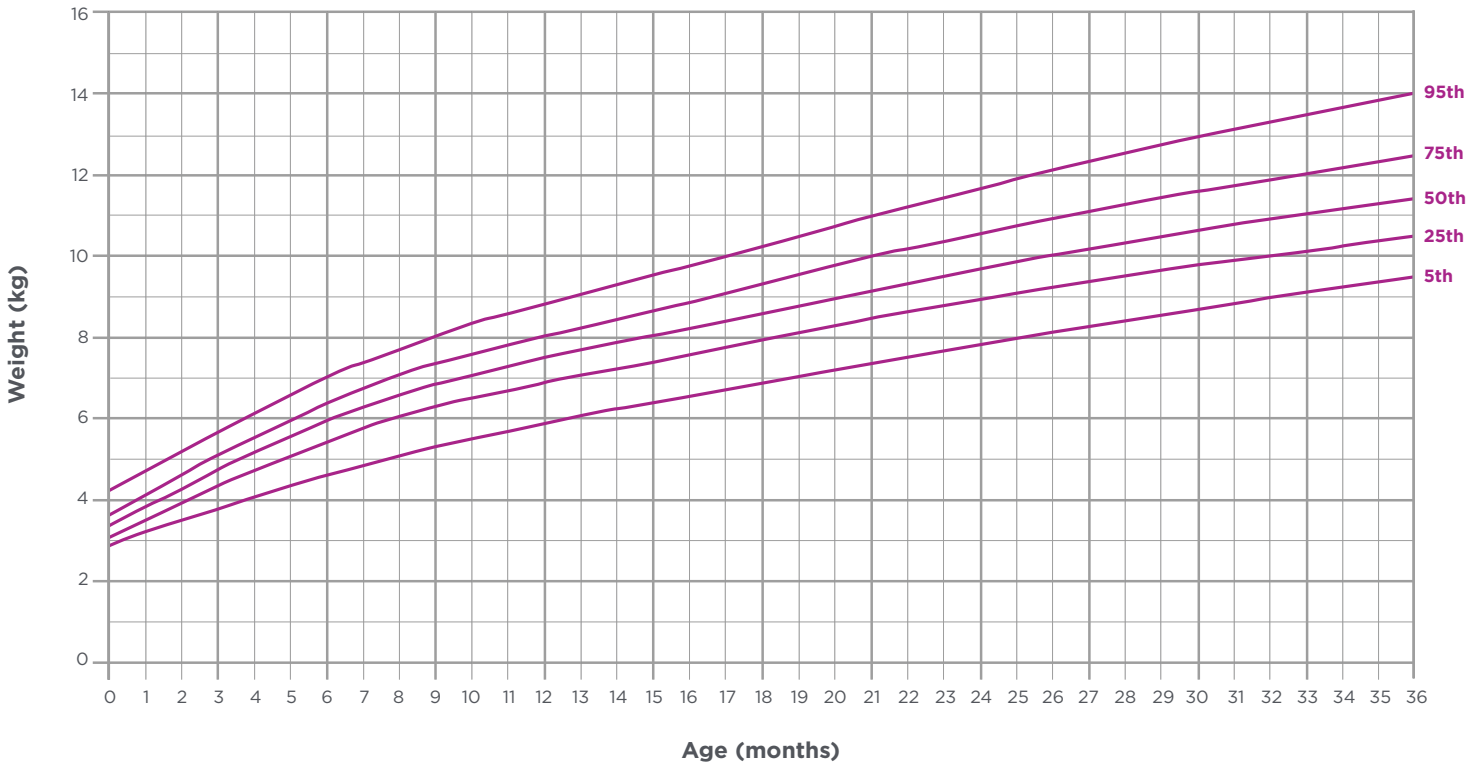
Derived from 4512 data points from 528 subjects.

Weight for Age
Males
Birth to 36 Months

Weight for Age
Males
2 to 18 Years

Weight for Age
Females
Birth to 36 Months

Weight for Age
Females
2 to 18 Years



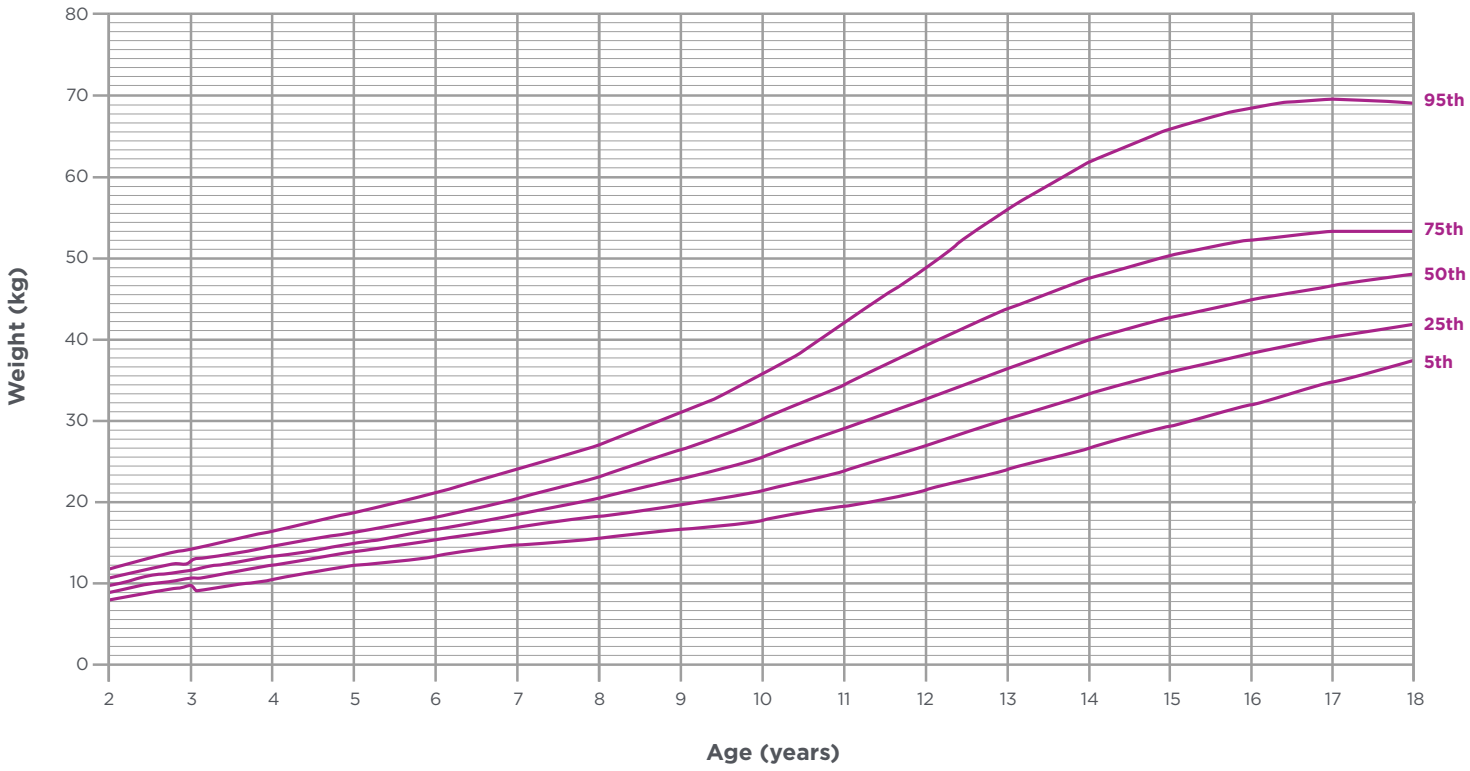
Derived from 3087 data points from 491 subjects.

Weight for Age
Males
Birth to 36 Months

Weight for Age
Males
2 to 18 Years

Weight for Age
Females
Birth to 36 Months

Weight for Age
Females
2 to 18 Years



Derived from 4236 data points from 482 subjects.

Weight for Height
Males
50 cm to 80 cm

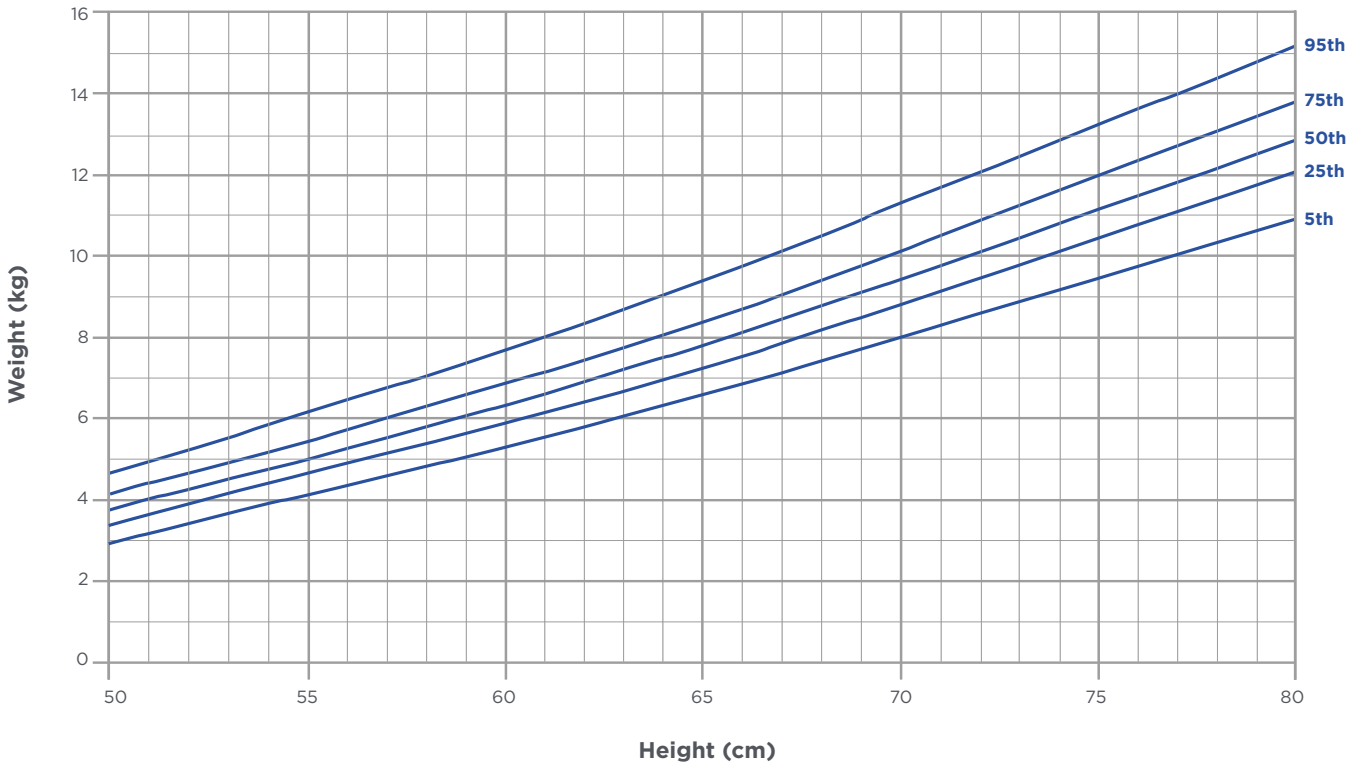
Weight for Height
Males
80 cm to 110 cm

Weight for Height
Males
110 cm to 140 cm

Weight for Height
Females
50 cm to 80 cm

Weight for Height
Females
80 cm to 110 cm

Weight for Height
Females
110 cm to 130 cm



Derived from 2822 data points from 493 subjects.

Adapted from: Hoover-Fong JE et al. *Orphanet J Rare Dis.* 2021;16:522.

Weight for Height
Males
50 cm to 80 cm

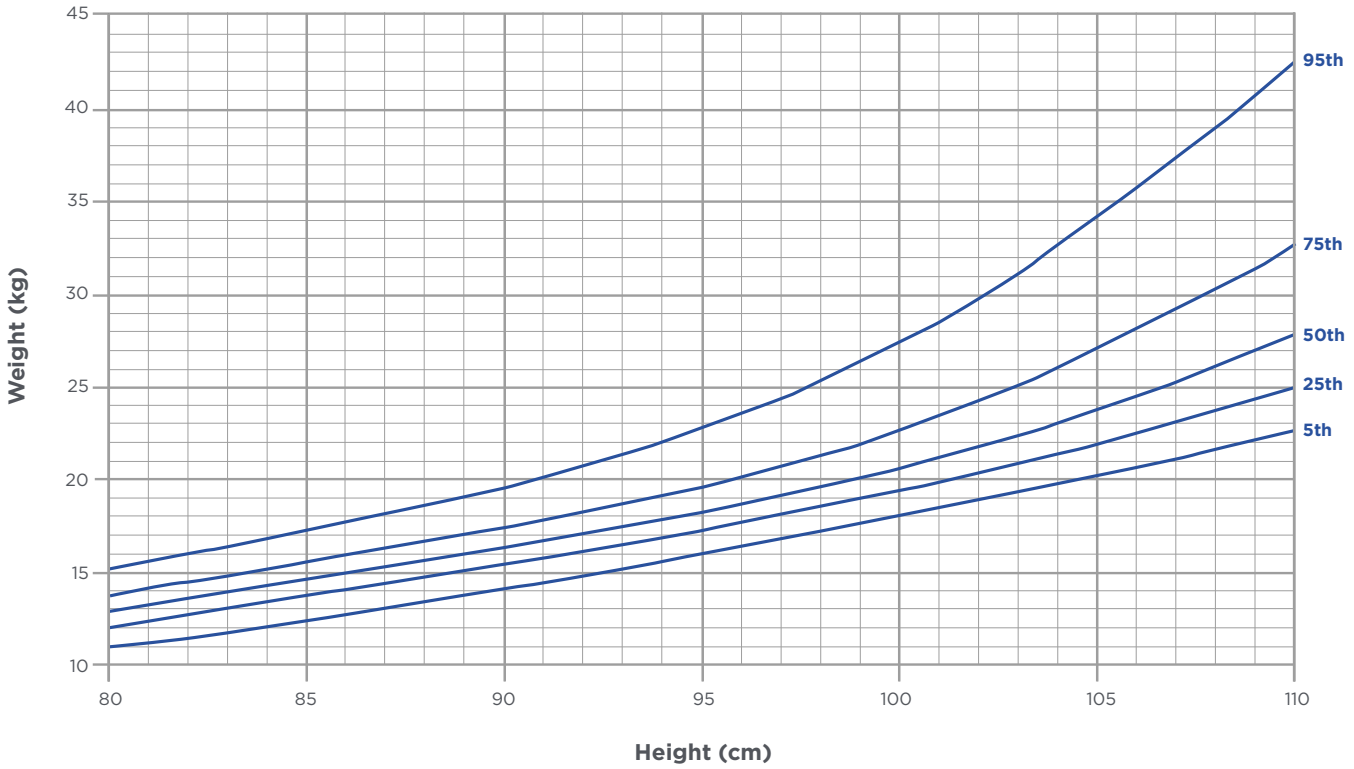
Weight for Height
Males
80 cm to 110 cm

Weight for Height
Males
110 cm to 140 cm

Weight for Height
Females
50 cm to 80 cm

Weight for Height
Females
80 cm to 110 cm

Weight for Height
Females
110 cm to 130 cm



Derived from 2180 data points from 413 subjects.

Adapted from: Hoover-Fong JE et al. *Orphanet J Rare Dis.* 2021;16:522.

Weight for Height
Males
50 cm to 80 cm

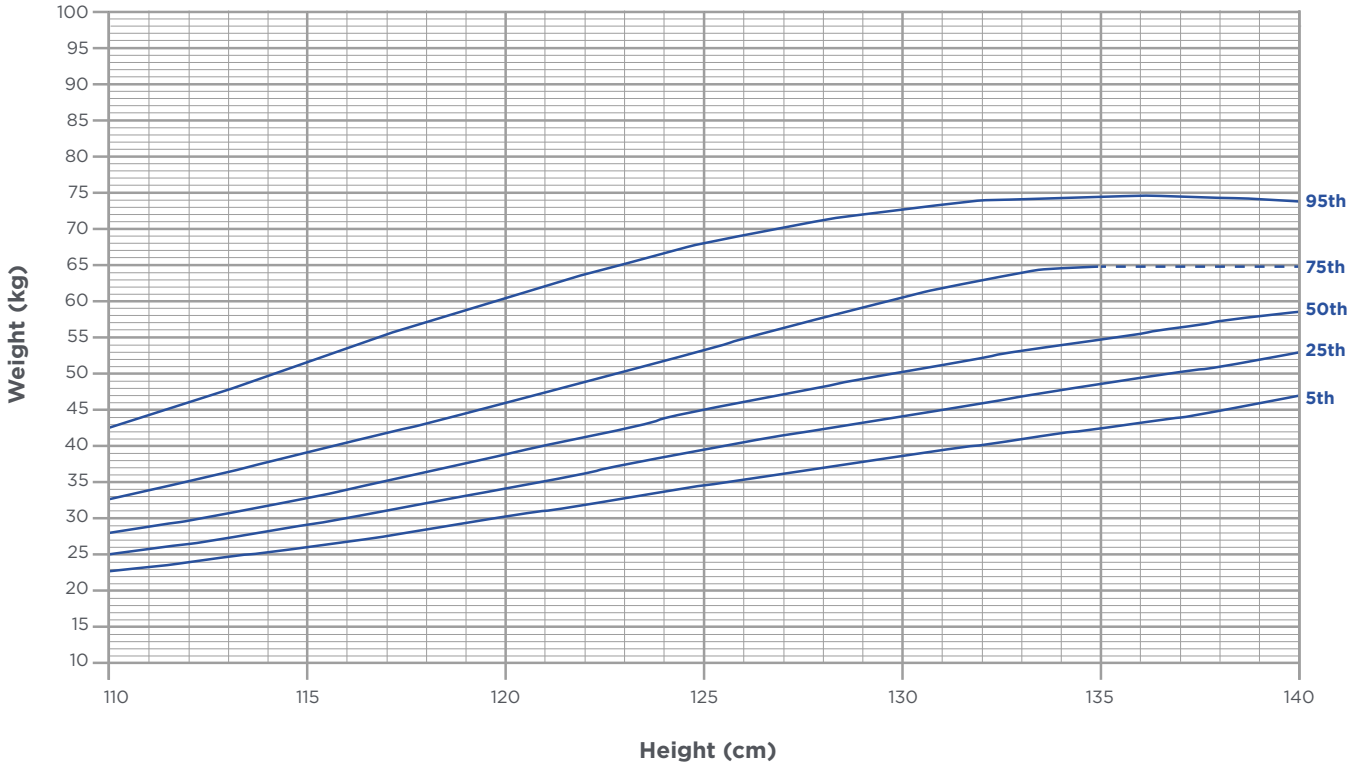
Weight for Height
Males
80 cm to 110 cm

Weight for Height
Males
110 cm to 140 cm

Weight for Height
Females
50 cm to 80 cm

Weight for Height
Females
80 cm to 110 cm

Weight for Height
Females
110 cm to 130 cm



Derived from 956 data points from 265 subjects.

Adapted from: Hoover-Fong JE et al. *Orphanet J Rare Dis.* 2021;16:522.

Weight for Height
Males
50 cm to 80 cm

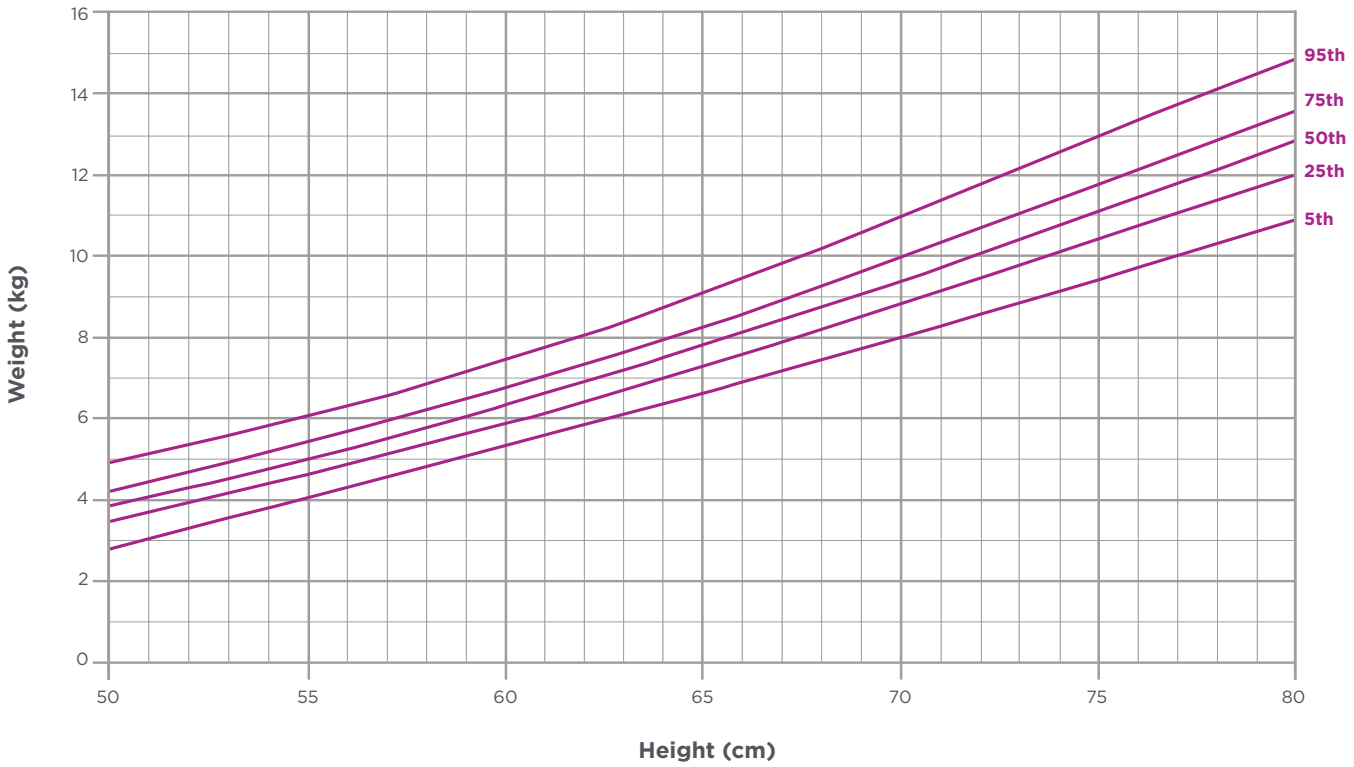
Weight for Height
Males
80 cm to 110 cm

Weight for Height
Males
110 cm to 140 cm

Weight for Height
Females
50 cm to 80 cm

Weight for Height
Females
80 cm to 110 cm

Weight for Height
Females
110 cm to 130 cm



Derived from 2478 data points from 440 subjects.

Adapted from: Hoover-Fong JE et al. *Orphanet J Rare Dis.* 2021;16:522.

Weight for Height
Males
50 cm to 80 cm

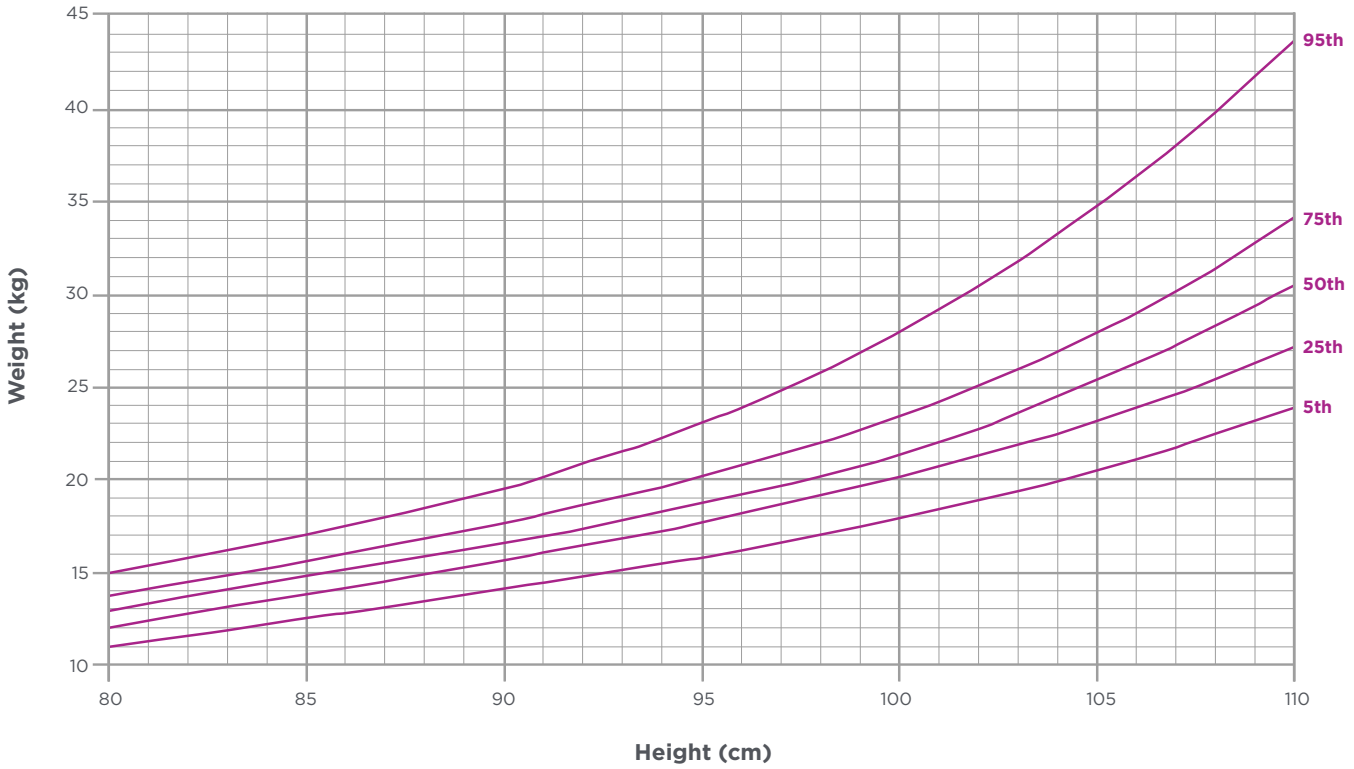
Weight for Height
Males
80 cm to 110 cm

Weight for Height
Males
110 cm to 140 cm

Weight for Height
Females
50 cm to 80 cm

Weight for Height
Females
80 cm to 110 cm

Weight for Height
Females
110 cm to 130 cm



Derived from 2420 data points from 388 subjects.

Adapted from: Hoover-Fong JE et al. *Orphanet J Rare Dis.* 2021;16:522.

Weight for Height
Males
50 cm to 80 cm

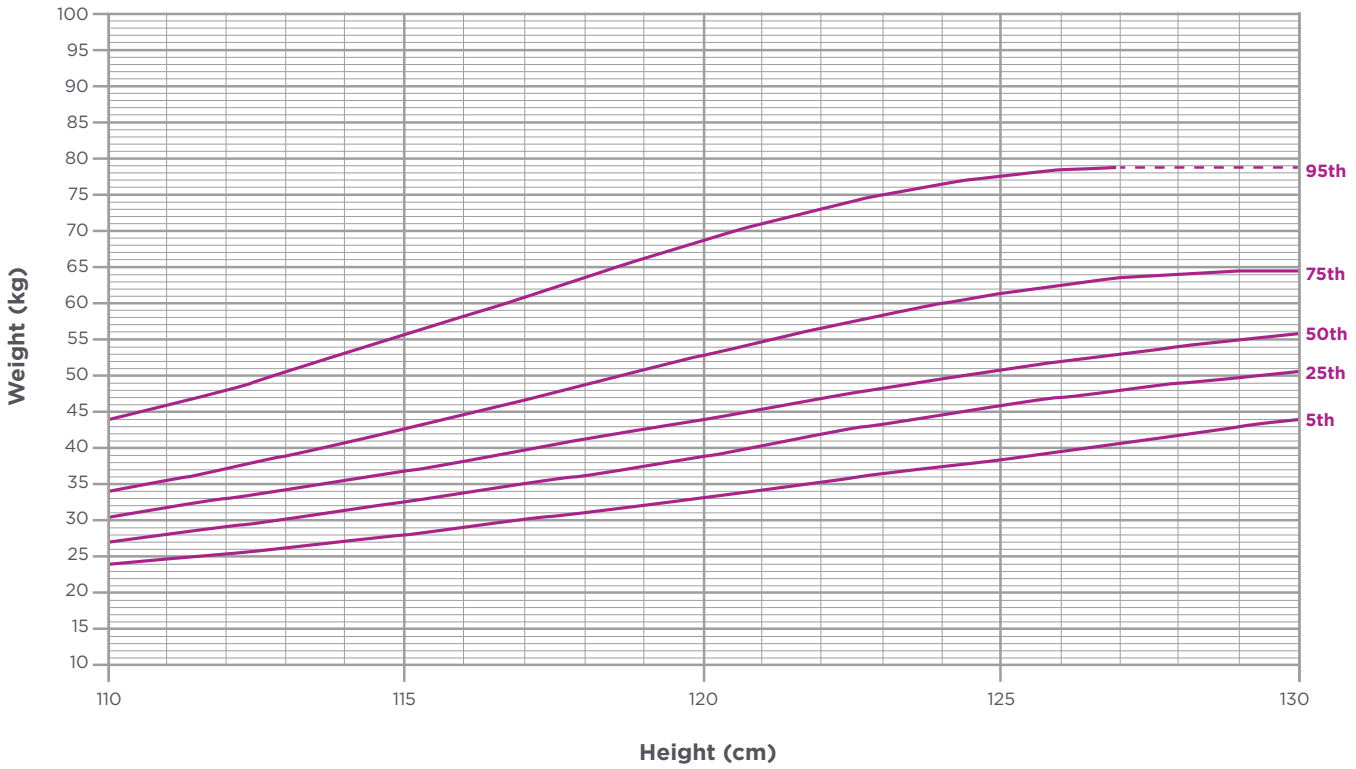
Weight for Height
Males
80 cm to 110 cm

Weight for Height
Males
110 cm to 140 cm

Weight for Height
Females
50 cm to 80 cm

Weight for Height
Females
80 cm to 110 cm

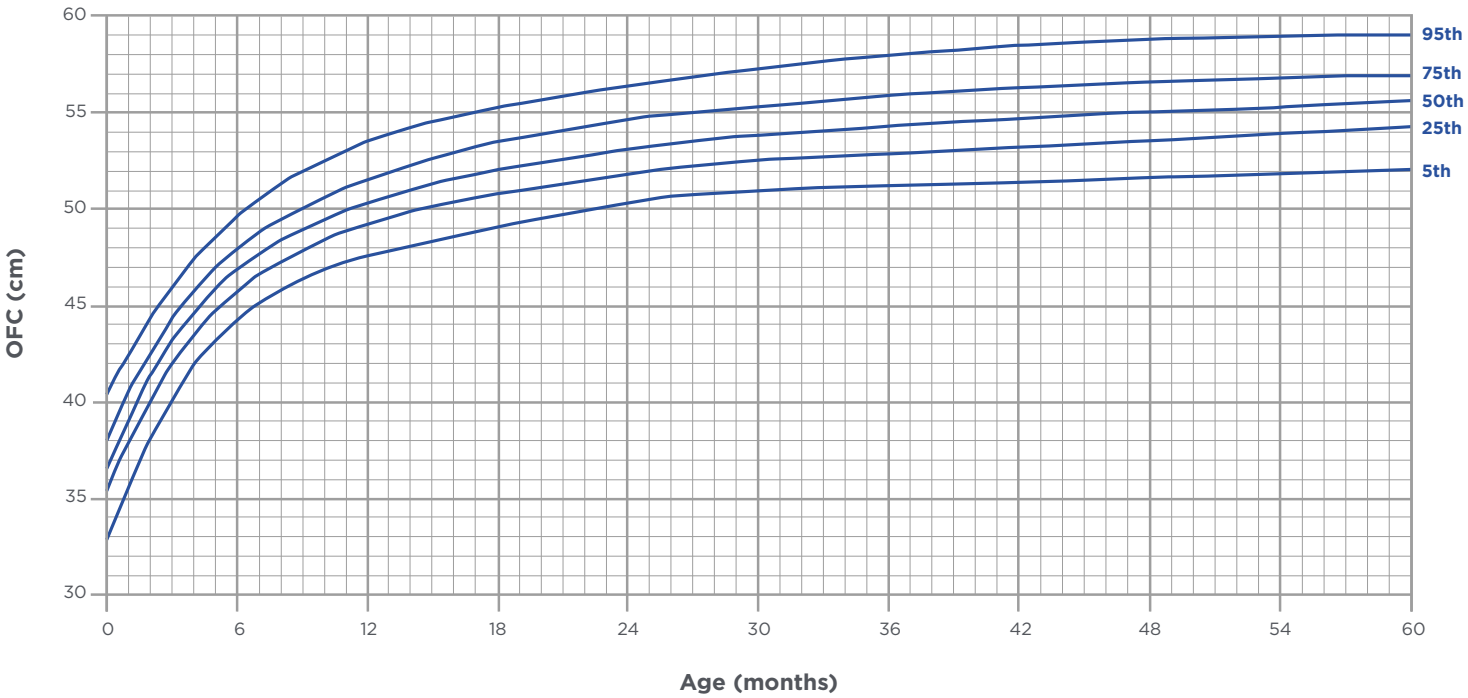
Weight for Height
Females
110 cm to 130 cm



Derived from 952 data points from 263 subjects.

OFC for Age
Males
Birth to 5 years

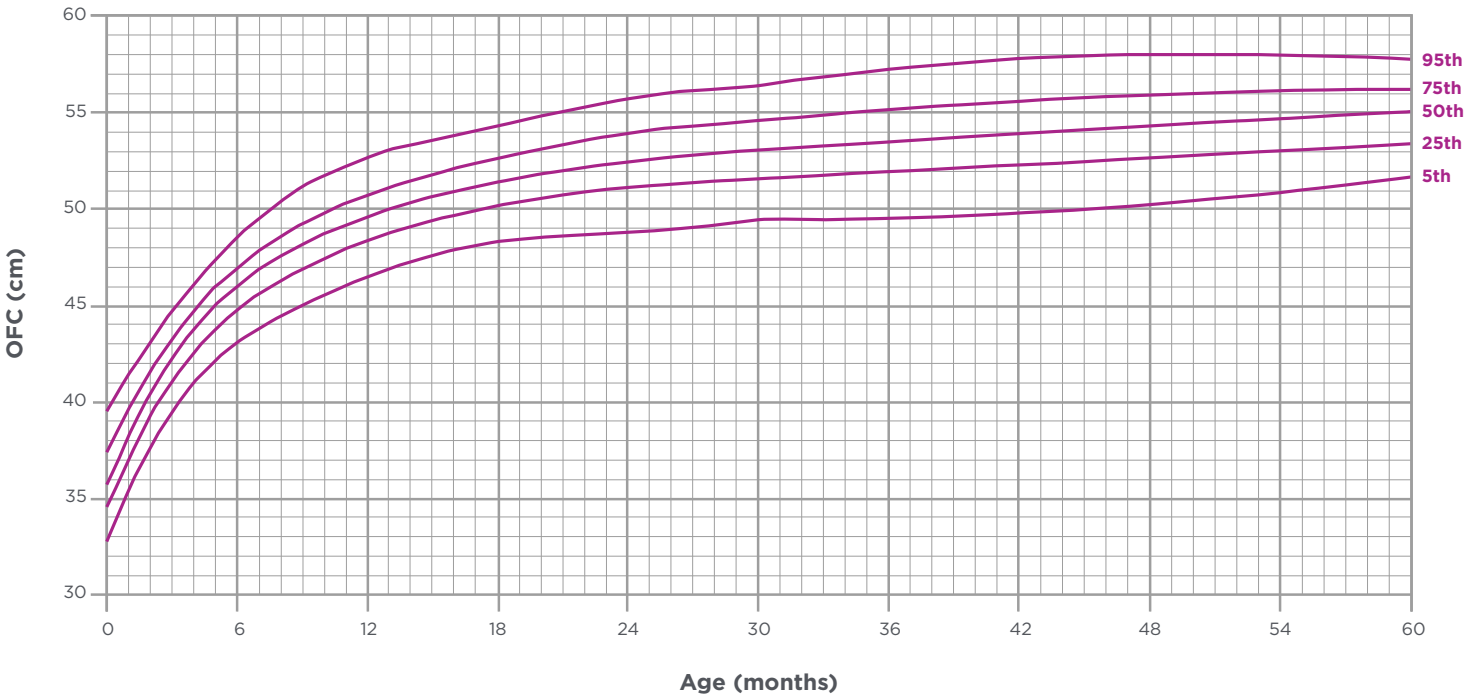
OFC for Age
Females
Birth to 5 years



OFC, occipital frontal circumference
Derived from 3449 data points from 534 subjects.

OFC for Age
Males
Birth to 5 years

OFC for Age
Females
Birth to 5 years



OFC, occipital frontal circumference
Derived from 3012 data points from 489 subjects.