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Dear Physician,

On behalf of the Rett Syndrome Natural History Study group, I am pleased to offer the following Rett syndrome growth references for clinical use. Derived through our advocacy support from the International Rett Syndrome Foundation and from data on over 700 affected patients, these references are an accurate representation of growth in Rett syndrome.

As a result of this project, we have gained insight into the patterns of growth in Rett syndrome which should help clinicians to interpret measurements of height, weight, and head circumference. Head circumference is expected to be smaller than the normative population, and, in fact, by 2 years of age the mean head circumference in Rett syndrome is lower than the 2<sup>nd</sup> percentile on normative references. When somatic measurements of girls with Rett syndrome are plotted on standard charts, they often lie near or below the lowest percentiles, raising concern for malnutrition or comorbid disease. However, the pattern of growth in girls with Rett syndrome reveals that average weight and height are expected to fall below the normative mean at 6 and 13 months respectively. The pubertal “growth spurt” observed as an increasing slope on the normative charts was not observed in girls with Rett syndrome. Ultimately, both weight and height in the average girl with Rett syndrome are lower than the 2<sup>nd</sup> percentile on normative references by age 12 years, despite adequate nutrition and aggressive medical management in the majority.

The average Body Mass Index (BMI) in Rett syndrome is similar to that of the normative population, and a normal BMI is a reassuring marker of health. However, the dispersion of BMI is much wider in Rett syndrome. This distribution suggests that girls with Rett syndrome are both more likely to become obese and more likely to fail to thrive than the normative population. Following height and weight velocity on these Rett-specific references will help to monitor these tendencies much more carefully than was possible on the CDC references, especially after age 12 when the majority of measurements fall in “uncharted territory” below the normative 2<sup>nd</sup> percentile.

These charts also include normative references for convenient comparison. Please note that the normative references presented are the British references. These were chosen because their age ranges suited comparison, and their statistical methodology far exceeded that of the CDC charts. Comparisons were made to the CDC and WHO charts, and for weight and height the differences were trivial. CDC head circumference was only available to 3 years, so comparison was not possible beyond then.

We hope you find these references useful in the clinical management of your patients. Further details are available in the published manuscript at [www.neurology.org](http://www.neurology.org). Please visit [www.rettsyndrome.org](http://www.rettsyndrome.org) to download the charts or contact the authors with any questions.

Yours truly,

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