



# Behavioral Health Nutrition

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## BHN Fact Sheet: Rett Syndrome

Rett syndrome (RTT) is a neurologic and genetic disorder. It occurs mostly in the female population at an estimated rate of 1 in 10,000 live births. Individualized nutrition evaluation and treatment throughout life is important to the growth, health, development and quality of life of the individual with RTT.

### General Information

Characteristic physical health and developmental features of RTT may include:

- Growth failure including a reduced rate of head growth
- Gradual decline in mental and physical function following a generally normal growth and development period; age of onset and severity of decline varies from child to child
- Abnormal muscle tone, spinal curvature and a wide variation in walking ability
- Abnormal nerves and muscles that cause blood vessels to constrict or dilate
- Loss of purposeful hand use with repeated hand movements (commonly hand wringing/washing/squeezing, or tapping)
- Partial or total loss of ability to speak and inappropriate laughing or screaming
- Abnormal breathing (rapid breathing or breath holding) and air swallowing
- Intense eye gazing
- Teeth grinding while awake
- Abnormal sleep patterns
- Poor response to pain
- Seizure disorders. The age of onset and severity of seizures vary
- Small, cold hands and feet
- Wide steps when walking
- Feeding problems
- Swallowing and chewing difficulty
- Gastrointestinal problems: including reflux and constipation

### Nutrition Concerns/ Implications

- Good nutrition including adequate fluid intake is critical to growth and overall health.
- Nutrient needs and feeding tolerance can vary greatly during the first twenty years of life.
- Feeding evaluation and gastrointestinal medical consultation are often indicated.
- Seizure medications can be associated with sleepiness, poor appetite, weight gain or weight loss. The Registered Dietitian Nutritionist (RDN) can suggest optimum nutrients based on medications.
- Scoliosis may require corrective surgery to improve health outcomes. Optimal nutrition is essential during the pre- and post-operative periods to help with healing.
- Bone health is important to minimize risk for fractures, periods of immobility, and loss of ambulation. Adequate calcium and Vitamin D intake are essential to help promote bone health. Researchers identified Vitamin D deficiency to be prevalent in females with RTT.

# BHN Fact Sheet: Rett Syndrome

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## Nutrition Tips and Advice

- An individualized nutrition plan is necessary to ensure adequate and appropriate nutrient and fluid intake.
- The nutrition plan should include goals to monitor and evaluate throughout the lifespan and in times of medical crisis.
- Caregivers and health care team members should contribute to the development of the feeding/eating plan.
- The feeding/eating plan may include: special diet and/or formulas; proper positioning; adaptive eating utensils, cup or plate; and feeding techniques to ensure safe intake of solid foods and liquids.
- Guidance and support by a Registered Dietitian Nutritionist is necessary when feeding tube placement is anticipated.
- A customized medical formula is often indicated when calorie needs are extremely low.
- Growth patterns should be evaluated using standard and RTT specialty growth charts.
- A weight for height goal should be established and monitored closely to promote optimal growth and prevent overweight or obesity, as these can be difficult to reverse.

## Resources for Further Information

The International Rett Syndrome Foundation (IRSF) at [www.rettsyndrome.org](http://www.rettsyndrome.org)

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More topics and resources available at [bhndpg.org](http://bhndpg.org).

This information does not take the place of medical advice. Please contact a Registered Dietitian/Nutritionist or medical doctor for more information.

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