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
continued

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

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More topics and resources available at 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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