

Health Matters

Rett syndrome is a unique disorder that most often begins to show itself in early childhood. It is primarily discussed as a neurological disorder, or a developmental disorder, associated with loss of acquired skills like speech and hand function. Health and medical issues may not always be the first issues that come to mind. However, there are some medical issues that children with RTT may experience over the course of their lifetime. For parents and caregivers, these can quickly become the most overwhelming and fearful aspects of the syndrome if we don't know what to look for, how to rule-it-in or how to rule-it-out, and how to treat and manage. At IRSF, we so often hear "if she could only tell us where it hurts, or if it hurts!". Believe that she is telling you!. We encourage you to trust your instinct about her baseline health, and seek medical attention from experts who can read her health clues, and determine if treatment is necessary and available. Not all clinicians are experts in Rett syndrome, but that should not diminish your confidence that they can become one with an open and collaborative relationship with you and your child.

In this section, we will provide information from the experts about medical concerns often seen in Rett syndrome, and recommended avenues for help. The most important thing to keep in mind is that:

- Not every child will experience all of these symptoms, and some may be free from all of them
- It is the educated caregiver who will help her most if she needs it
- These articles are to empower and guide you, but only you and your child's physicians know her best
- Do not be afraid to have hope. There are treatments and therapies available to combat most of these issues, and IRSF is deeply committed to accelerating research that will truly treat, and eventually reverse, all of them
- [Click here \(coming soon\)](#) to read more about clinics and clinical trials that are involved with this work.

Common medical concerns may include:

Epilepsy

- Neurology RTT Glaze IRSF June 2010 1.70 Mb

Disrupted Sleep

- Rett Sleep FAQ 882.60 Kb

Breathing Irregularities

Gastrointestinal Dysfunction

- Gastroenterology Issues in RTT K Motil Conf 2011 7.07 Mb

Growth and Nutrition

- Nutrition Focus Nov Dec 2008 1.78 Mb

Orthopedic Dysfunction

- Scoliosis Rett Syndrome 2009 Families 2.86 Mb

- Scoliosis Rett Syndrome 2009 Clinicians 181.90 Kb
- Orthopedics and Scoliosis Killian IRSF June2010.pdf (Coming soon)

Osteopenia and Osteoporosis

- Endocrinology Bone Issues I Holm IRSF Conf2011.pdf (Coming soon)

Spasticity

- Practice Parameter Drugs and Spacticity 286.01 Kb

Temperature Dysregulation

Anxiety and Behaviors

- Behaviors E Tierney May 2009 53.54 Kb

Sexual Maturity

- Womanhood Lane IRSF June 2010 48.00 Kb

Prolonged QT Interval

Anesthesia

Dental Health, Bruxism

General Good Health References

- Pediatric and Adult Preventive Care J Lane Conf 2011 1.31 Mb

Other

- Rett Syndrome and Mitochondrial Function Percy, March 2011 619.81 Kb