

Support Networks

Join one of IRSF's Support Networks TODAY. IRSF offers numerous support networks in an effort to provide the specific support tailored to the needs of you and your family need! These networks will provide you with the ability to communicate with others experiencing the same issues you are, allow you to form special relationships with others, and most importantly, will provide you with the much needed information you have been looking for. At this point in time IRSF offers the following networks: The Parents of Males with MECP2 Mutations Network, The Dads Network, The Grandparents Network, The Single Parents Network, The Educators Network and The Life After Rett Network.

These Networks will Strive To:

- Address the specific concerns of each individual group as they experience specific struggles of having a loved one with Rett syndrome
- Provide information in regard to care giving, emotional and physical demands, role within the family, relating to the child and other areas identified
- Provide a forum to exchange experiences and ideas
- Create a network directory
- Enlist willing volunteers in building awareness for Rett syndrome within their various communities
- Targeted Rett Gazette pieces
- Build relationships between members and IRSF
- Provide appropriate avenues for raising funds to support IRSF's mission

Join one of our many support networks today!

The Parents of Males with MECP2 Mutations Network - Parents and Individuals who care for males with Rett syndrome or a MECP2 mutation oftentimes feel isolated...you are no longer alone. This network will provide you with the ability to communicate with others experiencing the same issues you are, allow you to form special relationships with other parents and caregivers, and most importantly will provide you with the much needed information you have been looking for.

The Dads Network – As a dad to a Rett Angel, you are one of, if not the, most important person in your angel's life. Your child loves you and needs you. This network is a primarily email based community that will strive to help you understand Rett syndrome better as you cope the diagnosis and your child.

The Grandparents Network - Grandparents are such special people to begin with. However, a grandparent to a Rett Angel is even more special. These children (and your children) love you and need you. Even if you are not close-by in proximity, you can be in spirit by showing your love, care and concern. This network is a primarily email based community that will strive to help you understand Rett syndrome better as well as how you can help your children cope

with their diagnosed child.

The Single Parents Network - This special interest group provides the support needed to understand and overcome the unique obstacles that having a child with Rett syndrome while being a single parent brings to a family. This network, led by Regional Representative Lisa Rushin and IRSF Family Support Coordinator Lisa Hayden, will strive to help you in times of question or need as you face Rett syndrome as a single parent. It will be a forum for camaraderie, compassion and understanding amongst parents with similar situations. At this point in time, this group has been primarily housed on Facebook.

The Educators Network - If you are working with or have worked with a student with Rett syndrome, we want to hear from you! If you are the parent of a child with Rett syndrome, please let your child's teachers and therapists know about this newly established network! Professionals will be able to communicate through various social media outlets as well as participate in informational and educational conference calls, custom planned depending on the needs and interests of those involved. Registered teachers and therapists can participate at the level that is right for them but can be assured there is a sounding board and others available for questions, brainstorming and sharing of ideas.

The Life After Rett Network - Many parents and family members that have lost a loved one with Rett syndrome have asked IRSF to provide a bridge to others who understand; to provide a place to share feelings of grief and loss, and to share strategies for coping, healing, and staying involved with the Rett community in a meaningful way. In response, we have created a private Facebook group named the Life After Rett Network. We invite you to join.

Contact Jennifer Endres with any questions or concerns you may have. Call 1-508-362-2220 or email jendres@rettsyndrome.org