

## Where to Now?

Have you just received your Rett syndrome Diagnosis?

Getting the diagnosis of Rett syndrome is difficult, but there are many people who are willing to help you, beginning with IRSF. Here are a few places to start:

- Visit our website often to learn the most current, accurate information about Rett syndrome
- Join an IRSFonline communityin order to build relationships and a support network with other parents just like you
- Join the IRSF Partner program to stay connected with the Rett syndrome community through:
  - Newsletters; e-news alerts; discounts on Foundation merchandise, materials, conferences and education programs; special updates and announcements about research and self-help and education programs; and invitations to local clinics, events and program activities.
- Take the time you need to grieve. Feeling depressed and overwhelmed is very natural. Find a grief counselor who is familiar with special needs families.
- Reach out to others who share your Rett journey. IRSF can help you find others in your area.
- Make sure your child’s medical team is knowledgeable about Rett syndrome. IRSF can help provide information and can refer you to the nearest specialist. Find out what educational services are available for your child. Call the special education department of your local school system.
- Seek out information about financial assistance programs. Call the public health department, social work department of a local children’s hospital, your Developmental Disabilities Administration, or local ARC.
- Take care of yourself so that you will be able to better care for your child.
- Don’t try to plan for a lifetime in one day.
- Remember that you are not alone.