

## Resources

### FAMILY NETWORK

The Family Network brings together those in close proximity or who share similar interests and concerns about RS. Names are released only with specific written permission. Strict confidentiality is always maintained.

### WORLD WIDE WEB

The IRSF home page on the World Wide Web (<http://www.rettssyndrome.org>) provides more than 900 pages of up-to-date information about Rett syndrome and IRSF events, and includes links to scores of other resources.

### THE RETTNET

Our special mailing list, RettNet, is open to anyone interested in finding information to improve the well-being of girls with RS and their families. The email discussion group includes more than six hundred parents, siblings, teachers, therapists, physicians and friends. It is a tremendous resource for information and support, and is currently offered without charge as a membership service of the International Rett Syndrome Foundation.

### ELECTRONIC NEWSLETTER

Our electronic newsletter brings the Rett community the latest on research, family support, advocacy and other newsworthy items. When the news is there, our electronic newsletter brings it in timely fashion, and disseminates it using reader-friendly and plain language synopses of the latest discoveries.

### TOLL FREE HELP

A call to IRSF's toll free number, 1-800-818-RETT, is a comfort and resource for families. Whether it is for a physician referral, a connection to other families, information about IRSF events or just to talk over a problem, toll free help is just a quick phone call away.

### REFERRAL SERVICES

Making a referral to the appropriate local professional is an important function of IRSF. IRSF provides information on Rett syndrome that includes identifying and making the diagnosis, methods of management and care. IRSF keeps a listing of physicians indexed by state and country for parents to readily reach a specialist who understands Rett syndrome. Many parents have spent years traveling from one doctor to another never finding anyone to understand or help. This service fulfills a critical need to assist parents in locating helpful resources.

### PROFESSIONAL LIBRARY

Interest in Rett syndrome has increased dramatically over the last few years and more than 2000 papers have been published. Many of these articles can be viewed as abstracts or ordered through our website links. IRSF also maintains a video, audio and slide presentation library, which contain a wide variety of topics including research, parent support, therapy and care for the child with Rett syndrome. IRSF also maintains an online bibliography of all articles written on Rett syndrome. IRSF will soon feature an electronic Resource Center which will include access to many primary articles, databases, and powerpoint presentations through its website.

### NEWSLETTER

The IRSF quarterly newsletter is a vehicle for providing information on various techniques of management and care, emotional support to families, and current updates on medical and educational research. The newsletter fills an essential need for information, understanding and support and includes important "exclusive" articles by many professionals.

## ANGEL FUND

IRSF's ANGEL FUND was established to provide equipment and materials which enrich the lives of those with Rett syndrome. Grants up to \$200 are available to IRSF members who show financial need.

## ANNUAL CONFERENCE

The Annual IRSF Conference is a gathering of families and Rett syndrome experts from a variety of disciplines. Each year we meet in a different part of the U.S. See Family Support: Annual Conference for more details.

## BOOKS

You Will Dream New Dreams by Stanly D. Klein, Ph.D. and Kim Schive

Dancing in the Rain by Annabel Stehli

Changed by a Child by Barbara Gill

Special Kids Need Special Parents by Judith Loseff Lavin

From the Heart (On Being the Mother of a Child With Special Needs) by Jayne D.B. Marsh

Letters To Sam: A Grandfather's Lessons on Love, Loss, and the gifts of Life by Daniel Gottlieb

Fragile Innocence: A Father's Memoir of His Daughter's Courageous Journey by James Reston

After the Tears: Parents Talk About Raising a Child With a Disability by Robin Simons

The Rett Syndrome Handbook by Kathy Hunter

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