

IRSF Family Advisory Board International Rett Syndrome Foundation

Applications are now being accepted for the IRSF Family Advisory Board (FAB), and must be submitted by October 31, 2008 for consideration of one of four (4) open appointments commencing January 1, 2009.

Providing well-organized, sincere, sound, timely support is the best service that the IRSF Family Support staff can provide for families from the day they begin searching for a diagnosis through coping with day-to-day care issues after the diagnosis and beyond. Some of the best wisdom is learned from other parents, so we work to connect families with each other. Advice on how best to handle many care issues, medical issues, and communication/learning strategies are vague at best in the general medical, therapeutic, and education worlds so we strive to connect families with the professionals we know and trust to turn to. Local and regional groups are vital for connecting families with specific resources in their community given the diversity of support services available across the country. IRSF provides baseline support for these local and regional groups to foster and thrive. When families that have never held a fundraiser, educational seminar, awareness activity or social gathering become motivated to make a difference for those with Rett syndrome, we are there to help them host the most successful event they can – regardless of the size. When a family member, friend, caregiver, doctor, therapist or educator wants to know more about Rett syndrome, we are there to answer their questions.

However, if staff is the backbone of IRSF, then the unselfish commitment of our volunteer network is our heart and soul. Our network of expert families and friends who lend their talents, energy and resources to IRSF make our Family Support programs and services the best they can be.

The driver for these programs is the Family Advisory Board (FAB). The success of the FAB is dependent on having skilled, active, committed members. Your desire to serve on the board probably stems from a personal connection to Rett syndrome, but your rationale for serving on the board needs to be much more inclusive. It means more than just attending the meetings and having your name listed as a member. True board commitment means unselfishly giving your time, experience, and skills to advance the betterment of IRSF Family Support programs and services. It also means supporting the board team even when you disagree with a majority decision. You have to be motivated by a desire to see IRSF Family Support programs and services grow and develop for the good of all we serve.

The IRSF Family Advisory Board is comprised of at most 15 active members who have both personal and professional skills to best represent and advise on behalf of all families affected by Rett syndrome. We seek family members (mothers, fathers, grandparents, aunts, uncles, adult siblings, etc) who especially have expertise and cross-functional personal and professional skills in more than one of the following areas:

- An individual with RS: young child, school-age child, teen, young adult, older woman, an individual with RS who has passed away
- Family make-up: Married, single, divorced, remarried, adopted child
- Therapies: especially OT, PT, Speech/Communication, Nutrition, Marital/Family
- Medical
- Residential Placement

- Special needs law
- Support services
- Advocacy
- Public relations, media reporting
- Fundraising
- Programs/services/materials development and copywriting

FAMILY ADVISORY BOARD MEMBER DESCRIPTION

TITLE:	Member, IRSF Family Advisory Board
REPORTS TO:	Family Advisory Board Chairperson
PURPOSE:	To recommend, advise and consult on IRSF Family Support programs and services; to monitor the programs and services for success
TERM:	Two years
EXPECTED MEETING ATTENDANCE:	<ul style="list-style-type: none"> - Regularly attend FAB conference call meetings (approx 4/year) - Participate in standing committee meetings if a member - Actively participate on ad hoc working committees as needed - Attend and participate in special events as needed
OBLIGATIONS:	<ul style="list-style-type: none"> - Advise on policy and procedures - Advise, strategize, and recommend solutions for programs and services - Monitor and aim for short-term and long-range success
SPECIFIC DUTIES:	<ul style="list-style-type: none"> - Educate yourself about the needs of the people served - Attend meetings and show commitment to board activities - Be well-informed on issues and agenda items in advance of meetings - Contribute skills, knowledge and experience when appropriate - Listen respectfully to other points of view - Participate in organizational decision-making - Assume a leadership role in all board activities - Represent the organization positively to the public and in private - Contribute at least one article per term in your area of expertise to the Foundation newsletter

Members may only serve 2 consecutive terms of service. They are welcome to reapply for board service once they have rolled off for at least one term.

Questions? Email Paige Nues, Director, IRSF Family Support pnues@rettsyndrome.org or Dan Brinkhaus, FAB Chair, Dan_Brinkhaus@G1.com

Applications are now being accepted, and must be submitted by October 31, 2008 for one of four (4) open appointments commencing January 1, 2009. Applications can be:

Emailed to: admin@rettsyndrome.org

Faxed to: 513.874.3020

Mailed to: International Rett Syndrome Foundation
4600 Devitt Dr
Cincinnati, OH 45246

IRSF FAMILY ADVISORY BOARD (FAB) APPLICATION

Completed applications must be submitted by October 31, 2008 for term appointments commencing January 1, 2009. Applications can be:

Emailed: admin@rettsyndrome.org

Faxed: 513.874.2520

Mailed: International Rett Syndrome Foundation 4600 Devitt Dr Cincinnati, OH 45246

NAME: _____
FULL ADDRESS: _____
PHONE: _____
FAX: _____
EMAIL: _____

Please answer the following in detail:

WHAT IS YOUR RELATIONSHIP TO RETT SYNDROME AND AGE OF CHILD WITH RTT?

HOW LONG HAVE YOU BEEN INVOLVED WITH THE RETT SYNDROME COMMUNITY?

WHAT RETT SYNDROME ISSUES ARE YOU MOST INTERESTED IN?

PLEASE DESCRIBE YOUR CURRENT OR PAST FIELDS OF PROFESSIONAL EXPERTISE (Business, Project Management, Nonprofit, Education, Healthcare, Law, Legislative/Advocacy, Event Planning, etc):

WHAT SPECIAL SKILLS AND/OR EXPERTISE WOULD YOU BRING TO THE ADVISORY BOARD?

DO YOU, OR HAVE YOU, YOU SERVE(D) ON ANY OTHER BOARDS, RETT-RELATED OR OTHER?

WHAT CAN YOU CONTRIBUTE TO THE ADVISORY BOARD (time, energy, resources, personal connections, contacts)?

HOW HAVE YOU CONTRIBUTED TO THE ADVANCEMENT OF THE UNDERSTANDING OF RETT SYNDROME OR THE BETTERMENT OF THOSE LIVING WITH RETT SYNDROME IN THE PAST (personally, in your community, with IRSA, RSRF, or IRSF)?

WHAT WOULD MAKE YOU A GOOD ADVISORY BOARD MEMBER?

PLEASE PROVIDE AT LEAST TWO PERSONAL REFERENCES.
