



Family Advisory Board Description and Application - 2012

Applications must be submitted by Friday, October 28, 2011 for term appointments commencing January 1, 2012.

The IRSF Family Advisory Board is comprised of 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, personal and professional, in more than one of the following areas:

- An individual with RTT: young child, school-age child, teen, young adult, older woman, an individual with RTT 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

Providing well-organized, sincere, sound, timely support and offering connections to information and each other is the best service that the IRSF Family Support staff can provide for families. IRSF promises this from the day a family begins 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 - or contacted a legislator or policymaker - become motivated to make a difference for those with Rett syndrome, we are there to help them be as successful as they can, regardless of the size of event or activity. When a family member, friend, caregiver, doctor, therapist or educator wants to know more about Rett syndrome, we are there to answer their questions.

And if IRSF staff is the backbone of the foundation, it is the unselfish commitment of our volunteer network that 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. There are opportunities every day for any interested person to help IRSF in the critical areas of Advocacy, Awareness, Information, Support and Fundraising.

The driver for all of these programs is the Family Advisory Board (FAB). The success of the FAB is dependent on skilled, active, committed members. Our members desire to serve on the board because of a personal connection to Rett syndrome, but their rationale for serving on the board is much more inclusive. Our board of Family Advisors gives unselfishly of their time, experience, and skills to advance and better IRSF Family Support programs and services. They strive for unity, always supporting the board team even if they disagree with a majority decision. Members are motivated by a desire to see IRSF Family Support programs and services grow and develop for the good of all we serve.

We encourage you to apply. Please complete the application below and submit by OCTOBER 28, 2011.



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:** Three years
- EXPECTED MEETING ATTENDANCE:**
- Regularly attend FAB conference call meetings (approx 6/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:**
- 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:**
- 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
 - Attend and contribute to the annual IRSF Family Education and Awareness Conference if circumstances allow

Current terms of the FAB will commence January 1, 2012, with the option to reapply for a second consecutive 3-year term if all conditions of service were met in the first term. 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, at pnues@rettsyndrome.org or Clifford Fry, current FAB Chair, at cfry@rrc-inc.com

Applications can be:

Emailed to us at: admin@rettsyndrome.org

Faxed to: 513.874.2520

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



IRSF

INTERNATIONAL
RETT SYNDROME
FOUNDATION

IRSF FAMILY ADVISORY BOARD (FAB) APPLICATION

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Questions: Contact Paige Nues, Director, IRSF Family Support, at pnues@rettsyndrome.org or Clifford Fry, current FAB Chair, at cfry@rrc-inc.com

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

- 1. WHAT IS YOUR RELATIONSHIP TO RETT SYNDROME AND WHAT IS THE NAME AND AGE OF THE CHILD WITH RTT THAT YOU ARE RELATED TO?**
 - 2. WHAT IS YOUR CURRENT OR MOST RECENT PROFESSION?**
 - 3. HOW LONG HAVE YOU BEEN INVOLVED WITH THE RETT SYNDROME COMMUNITY?**
 - 4. WHAT RETT SYNDROME ISSUES ARE YOU MOST INTERESTED IN?**
 - 5. WHAT SPECIAL SKILLS, EXPERTISE, OR LEADERSHIP EXPERIENCE WOULD YOU BRING TO THE ADVISORY BOARD?**
 - 6. DO YOU, OR HAVE YOU, SERVE(D) ON ANY OTHER BOARDS, RETT-RELATED OR OTHER?**
 - 7. WHAT CAN YOU CONTRIBUTE TO THE ADVISORY BOARD (time, energy, resources, personal connections, contacts)?**
 - 8. HOW HAVE YOU CONTRIBUTED TO THE ADVANCEMENT OF THE UNDERSTANDING OF RETT SYNDROME OR THE BETTERMENT OF THOSE LIVING WITH RETT SYNDROME (personally, in your community, with IRSF, or other RTT associations/organizations)?**
 - 9. WHAT WOULD MAKE YOU A GOOD ADVISORY BOARD MEMBER?**
 - 10. PLEASE PROVIDE AT LEAST TWO PERSONAL REFERENCES.**
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