

Regional Representative - Upstate New York

Contact Information

State	Name	Email	Phone	Upstate
<p>Shirley Hurlburt and I live in Liverpool, NY with my husband Paul, my daughter Kaila MacLaury who is 7, and our newborn Kinley Rose Marie. Kaila was diagnosed with Rett Syndrome August 6, 2004 when she was 3 years old. It was after Kaila was first diagnosed with Autism that I became involved with advocacy. I joined a parent group that was just starting out called Families for Effective Autism Treatment of Central New York (F.E.A.T. of CNY). I have been a part of that group since 2004 and I have held officer positions and served as a board member. I have been able to be a part of a wonderful group that has grown by leaps and bounds and is making a difference in the lives of children who have Autism each and everyday. I decided in 2006 to begin working as a Medicaid Service Coordinator because I wanted to help other families with advocacy, services, and supports. I also attended and graduated from Partners in Policymaking; a leadership training program that is offered in many states for individuals who have a disability, parents, and family members. This training provides knowledge about issues and policies related to disability, and develops participants competencies to become more effective in influencing policy development at all levels. I enjoy helping families learn about services and supports and I hope I can make those connections for families who live with Rett Syndrome.</p>				

Events

Fundraisers	Family Gatherings	Support Groups
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State Specific Information and Services

Information and Links to State Resources

Recommended Professionals

Doctors	Therapists	Schools	M
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IRSF has not performed any background research on these individuals and in no way endorses any opinion on the professional expertise or experience of the listed individuals. The inclusion of any professional on this list does not indicate a recommendation or referral by IRSF or its staff.

Helpful Hints and Personal Messages

Unique Ideas and Suggestions	Messages from Individual Regional Reps
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Local Families