

## Staff

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- Stephen E. Bajardi, Executive Director
- Steven Kaminsky, Ph.D., Chief Science Officer
- Janice Ascano, Ph.D., Manager of Grants and Research
- Jane Lane, RN, BSN - Family Program Manager
- Jennifer Endres, Family Resource Manager
- Mary Joyce Griffin, Administrative Officer
- Paige Nues, Director of Family Support
- Lisa Hayden, Family Support Communications Program Manager

Stephen E. Bajardi

Executive Director

Stephen E. Bajardi is the Executive Director of the International Rett Syndrome Foundation. Steve has a strong background in the voluntary health nonprofit sector, especially in fundraising, public policy and management. He has worked at the executive level for the National Kidney Foundation, National Hemophilia Foundation, Huntington's Disease Society of America, the Greater New York March of Dimes and the Juvenile Diabetes Foundation. Steve is currently a Board Member and Treasurer of the National Organization for Rare Disorders (NORD).

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Steven Kaminsky, Ph.D.

Chief Science Officer

Dr. Kaminsky joined the International Rett Syndrome Foundation in January of 2012. He came to the Foundation after serving 11 years as the Vice President of Research for the Uniformed Services of the Health Sciences. While at USU, Dr. Kaminsky's interest was in faculty development. During his presence, the research programs grew to the highest levels in the school's history. USU, as published in August 2011 by the Chronicle of Higher Education, was number one in the category of largest gain in federal funds for research and development in science and engineering between 1999 and 2009. This growth in research funding was tied to the hard work of many researchers and staff under Dr. Kaminsky's leadership during his tenure as VP.

Originally from Binghamton, NY, he holds a Bachelor of Science Degree from Hobart College, Geneva, NY. While at Hobart Dr. Kaminsky was an All American Lacrosse player and an All East Coast Football player. He received a Masters of Science Degree in biology from Northern Michigan University and his Doctor of Philosophy in Pathology from the State University of New York at Buffalo. During his doctoral work at Buffalo, Dr. Kaminsky received two national awards; the Mead Johnson Award for Excellence in Research and the James A. McLaughlin Award for research in infectious disease.

Dr. Kaminsky did his postdoctoral fellowship at the Cancer Center of the Strong Memorial Hospital at the University of Rochester. At Strong Memorial Hospital he investigated the role of oncogenes in normal development. He was promoted to Instructor at the end of the second year of his fellowship. In 1985 Dr. Kaminsky was appointed to the rank of Assistant Professor in the Department of Pathology at the University of Buffalo where he studied the genetics of bone marrow transplantation.

In 1991 Dr. Kaminsky joined the National Institutes of Health as the Program Officer of the Developmental Genetics Program at the National Institute of Child Health and Human Development. At NICHD he worked on many trans-NIH projects and received an NIH Merit Award for his efforts. In 1995 Dr. Kaminsky was invited to the Baylor College of Medicine as the Vice Chairman of the Department of Molecular and Human Genetics at the Baylor College of Medicine. At Baylor he was part of the team that built the Department into one of the largest Genetics Program in the United States.

Dr. Kaminsky and his wife, Diana, have two children and they live in Urbana, MD. He enjoys bike riding, running, hunting, wood working, dancing and golfing in his free time.

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Janice Ascano, Ph.D.

Manager of Grants and Research

Janice Ascano joined the International Rett Syndrome Foundation in July 2011 as the Manager of Grants and Research. Prior to joining IRSF, Janice was teaching Chemistry at Hunter College and finished a postdoctoral fellowship at Rockefeller University. She received her doctorate degree from the University of Cincinnati and trained in the areas of cell-cell communication, signal transduction, and gene regulation. Janice is from the Chicago area, and, as an

undergraduate student, she studied biochemistry at the University of Illinois at Urbana-Champaign. She then worked at Abbott Laboratories. As the Manager of Grants and Research, she facilitates the grant-making process that includes soliciting applications, organizing the peer-review process, and managing post-award activities. Janice also works closely with the CSO to ensure that there is a coordinated flow of medical and scientific information from the investigators to the general public. Janice is married to her husband, Manny, who is a research scientist that works in the area of RNA molecular biology/post-transcriptional gene regulation in the nervous system that pertains to Fragile X Syndrome and Autism Spectrum Disorders. They have two lovely children, Ben (age 6) and Claire (age 2).

"I absolutely find working for IRSF to be very gratifying! As a scientist, I thought I would find my motivation to help others at the lab bench, ; but I soon realized that I didn't feel personally connected to those I could potentially help. At IRSF, I have had the pleasure of meeting extraordinary clinicians and scientists and the amazing families who are so dedicated to the well-being of these precious angels. As the Manager of Grants & Research, I am highly enthusiastic to use my scientific training to facilitate the grants program of IRSF and will strive towards achieving IRSF's mission, and I now feel extremely delighted to help make a difference."

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Jane Lane, RN, BSN

Family Program Manager

IRSF is pleased to announce the appointment of Jane Lane, RN, BSN to the IRSF team as Family Support Program Manager in January of 2009. Jane, under the tutelage of Alan Percy, MD has more than sixteen years experience as a research coordinator and manager in child neurology and the Civitan International Research Center at the University of Alabama at Birmingham, specifically related to the study of epilepsy in neonates and movement disorders including Tourette syndrome, Huntington disease, and Rett syndrome. Jane received a BS in Microbiology from Mississippi University for Women and a BS in Nursing from the University of Alabama. During the past six years she has worked exclusively with Rett syndrome, serving as Project Manager for the Angelman, Rett, and Prader-Willi syndromes consortium of the Rare Disease Clinical Research Network. The Natural History study of Rett syndrome and MECP2 mutations alone has enrolled nearly 700 females and males with the disorder. She has co-authored over 25 publications, many pertaining to Rett syndrome.

Jane serves as a member of the RettSearch Study Group, an international collaboration related to the organization of clinical trials for Rett syndrome and acts as a consultant to the International Rett Syndrome Foundation for medical issues. She serves on the board of the Southeastern Rett Syndrome Alliance as a professional advisor. Ms. Lane has spoken numerous times on the topic of medical issues in Rett syndrome and on issues related to the maturing woman with Rett syndrome. As such, she has broad experience with respect to the medical issues associated with this disorder. IRSF is honored to bring Jane's extensive knowledge, compassionate care, and optimistic attitude to families as part of our mission of serving Rett families throughout the world.

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Jennifer Endres

Family Resource Manager

In her role as Family Resource Manager, Jennifer acts as a liaison between the Foundation and families affected by Rett syndrome providing prompt information, support and assistance.

Jennifer obtained her masters degree in Education. Formerly a 1st grade and special needs teacher, she uses her background of working with parents and children in her position as Family Resource Manager.

Jennifer and her husband, Justin, became involved with raising funds for Rett syndrome research immediately after they learned of the diagnosis of their daughter, Jillian. Jillian, born in 2003, was diagnosed at the age of 17 months. Jennifer and Justin also have two sons, Griffin and Colin. The Endres family holds their annual Cape Cod Strollathon each spring. With the help of family members and friends, they have raised over \$600,000 in six years.

“Becoming involved with the Foundation has been one of the most rewarding experiences I have had in my life. I truly enjoy helping families on their journey with Rett syndrome. Since I walk the road every day, I understand with compassion how the families are feeling. Helping a family past their anguish and despair and allowing them to see the hope and light is what makes my job so gratifying.”

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Mary Joyce Griffin

Administrative Officer

Mary Joyce Griffin joined the Rett Syndrome Research Foundation in August of 2000 and has been a champion of the Foundation's mission ever since. MJ, as she is known in the office, is responsible for the daily administrative activities of

the organization. MJ's responsibilities are numerous including maintaining our database, processing donations, and accounts payable, as well as providing administrative and accounting support for our special events, annual scientific symposium and grant process. Mary Joyce has been married to her husband Garry for 35 years and has two adult children. She came to the Foundation from the Cincinnati Public School system. MJ has had an opportunity to meet many children affected with Rett syndrome and is personally committed to helping IRSF eradicate Rett syndrome.

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Paige Nues

Director of Family Support

Connection to RTT: Daughter, Katie (8)

Paige Nues, Director of Family Support, IRSF, dedicates her time to providing a safety net of accurate information, emotional support, and connections for the families, caregivers, and support teams of children with Rett syndrome. She seeks to educate families, caregivers, health providers and educators about the medical, educational, legal, financial, and social supports and research discoveries necessary to successfully care for an affected individual with Rett syndrome at various stages of her life. Paige has served on the Board of Directors, as a Regional Representative, and is parent founder of Katie's Clinic for Rett Syndrome at Oakland Children's Hospital. She enjoyed a successful career in sales, marketing, and business development with Fortune 500 companies prior to her daughter Katie's diagnosis of Rett syndrome in 2003. She and her husband Jesse live in California, proud parents of three extraordinary girls.

"Where you put your efforts is where you get results." It takes a team of caring family and friends, educated physicians, trained therapists, willing educators, and an open-minded supportive community to raise a child with Rett syndrome to reach her greatest potential. We will discover real treatments that will lead to a reversal of symptoms, but finding these treatments will take funding, time, and brilliant scientific minds. It is greatly through IRSF's efforts, dedication and careful stewardship of donations that we have the funding and people-power to achieve the results we all want. As IRSF's Director of Family Support, I commit all of my efforts into strengthening that safety net of support and information that gives families the direction, strength and connections they need to care and advocate for their child with Rett syndrome today. Our girls deserve this, and so do our families that support them.

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Lisa Hayden

## Family Support Communications Program Manager

Lisa Hayden joined the International Rett Syndrome Foundation just after graduating from Miami University in May of 2008 with a Bachelor of Arts degree in Strategic Communications as well as a Thematic Sequence in Management. Lisa interned as Assistant Event Coordinator for a country club in Cincinnati and has plenty of work experience under her belt. Lisa brings a host of talents and a bubbly, caring, compassionate personality to the Foundation. Lisa excels at accomplishing the tasks she sets out to do with energy, enthusiasm, and excellence. As Communications Program Manager, Lisa is committed to furthering the mission of the International Rett Syndrome Foundation through providing programs and services for the families impacted by Rett syndrome.

"This is the beginning of a new day. God has given me this day to use as I will. I can waste it or use it for good. What I do today is important, because I am exchanging a day of my life for it. When tomorrow comes, this day will be gone forever, leaving something I have traded for it. I want it to be a gain, not loss; good, not evil; success, not failure; in order that I shall not regret the price I paid for it.' – I love being able to make a difference every day through what I do. Though I am not directly related to an individual with Rett syndrome, I have become very connected to these girls. I am passionate about helping people and our girls need all the support we can give them. I am blessed to be a part of this team."

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