

## Board of Trustees

Please click on any trustee's name below to read their profile:

- Kathryn Schanen Kissam - Chair
- Steve Gallucci - Vice Chair
- John Corpus - Treasurer
- Christian McMahan - Secretary
- Dr. Richard Altschuler
- Dan Brinkhaus
- Eric Diamond
- Bill Farnum
- Michael Joyce
- Sean Lebson
- Karen Nussle
- Barry Rinehart
- Kenna Seiler
- Rajat Shah

Kathryn Schanen Kissam - Chair

Founder, Denovo Communications

Connection to RTT: Sister of RTT Clinician and Researcher, Dr. Carolyn Schanen, DuPont Children's Hospital

Kathryn Schanen Kissam is a branding, public affairs and issues management consultant. Her clients include Fortune 500 companies, agencies, and law firms throughout the United States. Prior to forming her own consulting business, Kathryn was the Chief Marketing Officer and Founder of Evolve24, a technology-based issues management company. Kathryn also worked for Monsanto Company of St. Louis Missouri for 13 years in various leadership capacities and served on the boards of the Monsanto Fund, The Pharmacia Foundation and The Missouri Historical Society. She is a recent graduate of Leadership Metro Richmond and a frequent speaker at branding and corporate citizenship conferences.

Kathryn's strong communications, marketing and public policy skills, coupled with her significant strategic planning and fund development experience, have made her an effective chairman for IRSF. Kathryn has raised significant dollars and pro-bono in-kind donations for IRSF, primarily earmarked for research.

"I look into the hopeful eyes of our girls and I feel compelled to help those impacted by Rett syndrome. As the sister of a RS researcher, I know that treatments and eventually a cure are out there waiting to be discovered. I am committed to being a part of that process. I believe I can help IRSF accomplish growth in the research arena while increasing its advocacy, family support and awareness efforts. Today, IRSF's most critical need is fund development to support our aggressive growth plans. I feel blessed to have formed so many meaningful relationships with the families and with the IRSF staff and board. I am grateful for the opportunity to serve."

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#### Steve Gallucci - Vice Chair

Steve is a Partner in the New York office of Deloitte & Touche. Steve and his wife Maura have been active in raising funds for Rett research after their daughter, Olivia, was diagnosed in April of 2001. From 2004 until 2006, Steve served as the Chairmen of the Board Of Trustees for RSRF. Together they served as the co-chairs of the inaugural 2002 Reach for A Cure NY Benefit which helped broaden RSRF's network of support in the New York City metro area and raised more than \$1,000,000 for research supported by RSRF.

He is a graduate of Providence College and earned his MBA from the University of Notre Dame.

Steve and Maura live in New Rochelle, New York with their 4 children, Olivia (RTT), Christophe, Isabelle and Peter.

"The funding of research towards treatments and a cure for Rett syndrome will have wide ranging benefits towards the advancement of neurological research. I am feel privileged to help lead in this effort. Our science program is on the cusp of breakthroughs that we believe give hope to all those who suffer from Rett syndrome and the related neurological disorders."

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#### John Corpus - Treasurer

Samantha was diagnosed with Rett Syndrome at age 3 ½. Since Samantha's diagnosis, John and Kathy Corpus have been on a crusade to help find a cure for their beautiful baby girl who is now 8 years old. Samantha is the middle sister to 2 two brothers, Julian (11) and Jacob (6). The Corpus Family resides in Alamo, CA. When John is not along side his family he is actively fundraising for the Rett syndrome cause. For the past two years, John and his family has hosted the Samantha Corpus Golf tournament at the Blackhawk Country Club in Blackhawk, California along with other fundraising efforts to help increase public awareness and fund research. Through John's tireless fundraising ventures, he and his family, friends and supporters have raised over \$300,000.00! Samantha is John's inspiration that keeps him persevering

to ultimately find a cure.

John is the Vice President of Enterprise Sales at Visage Mobile, where he is responsible for sales and customer experience for the Visage Enterprise Mobility solution.

“The power of the smile is overpowering. Many of our girls have smiles that melt our hearts, captivate us and motivate us. My daughter’s smile has given me strength I never knew I had before. I want to use this new found strength to help support the IRSF mission and provide the continued awareness that will allow IRSF to reach new heights in fundraising, providing research support and family support services. The involvement of our family, friends and community is a must. As a united force, we can achieve the IRSF mission and provide our girls with continued care and hope for a cure. From the smile in Samantha to the strength in me... together with IRSF we will find new hope to keep the smiles of our daughters endless.”

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Christian McMahan - Secretary

Christian is Chief Marketing Officer and Senior Vice President of Heineken USA, located in White Plains, NY. Heineken USA, a fully owned subsidiary of Heineken International, is one of the largest beer importers in the US including brands such as Heineken, Heineken Light, Amstel Light, Newcastle Brown Ale, Dos Equis, and Tecate.

Christian and his wife Ariane serve as co-chairs for the annual Boston Food & Wine Festival as well as being actively involved in the Reach for a Cure Benefit in NYC. Additionally, Ariane serves as an IRSF Regional Representative for Connecticut and Rhode Island. They both hold Bachelor of Science degrees from the University of Massachusetts at Amherst.

Christian and his family reside in Fairfield, CT. He and Ariane, have three children, Keilly (RTT), Keegan, and Avery.

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Dr. Richard Altschuler

Professor, University of Michigan, Ann Arbor, Michigan

Connection to RTT: Daughter, Leah (15)

Rick served two terms on Board of Directors of the International Rett Syndrome Association, chairing the Research Committee. He is now serving on the Board of Directors of the International Rett Syndrome Foundation.

"I have been doing research and teaching in neuroscience for over twenty-five years and bring an understanding of brain function, brain disorders and of basic research. I bring the viewpoint both of a neuroscientist and a parent of a child with Rett syndrome. Research on Rett syndrome has reached an exciting point in its development where it is poised for major advances that will lead to improved treatments and interventions to dramatically improve quality of life. Basic research must continue to advance and be supported and will also be transitioning to translational and clinical studies. IRSF has an important role to fill in making all of this possible. I also have a strong commitment to my daughter with Rett syndrome and her potential. IRSF has an important role to play in helping her and other children with Rett syndrome reach their potential through a broad research program, family support and advocacy."

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Dan Brinkhaus

Dan and his wife Lisa first became enthusiastically involved in the pursuit of a cure and promoting public awareness of Rett syndrome in 2000 when their first child, daughter Sara, was diagnosed with Rett syndrome at two years of age. In October of 2001 Dan founded the Minnesota Rett Syndrome Research Association, and since has passionately led a fundraising charge and spread Rett syndrome awareness throughout the community when and where possible.

Dan has over 17 years of broad software support and development experience, and maintains a long-standing career with the international mailing and software mogul, Pitney Bowes. Dan has held leadership positions on a number of boards such as the Information Technology Advisory Board for the Minneapolis Community and Technical College, the Minnesota Rett Syndrome Research Association, the Special Education Parent Advisory Board, as well as served as the inaugural Chairperson of the IRSF's very own Family Advisory Board.

"I am thrilled to have the opportunity to engage at the board level and fully commit to support IRSF's balanced multi-pronged mission of Advocacy, Awareness, Support, and a continued zealous pursuit of better treatments and a cure to Rett syndrome."

Dan and his family reside in a rural Minnesota community just south of Minneapolis called New Prague. He and Lisa have two children, Sara (RTT) age 10 and Ryan age 5.

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## Eric Diamond

Eric is a Vice President and Trader at Goldman Sachs Group Inc. in New York. He has a bachelors degree in Economics from Stony Brook University and an MBA from Pace University. He lives in East Brunswick, New Jersey with his wife Robin and his two daughters Jillian (10) and Abby(8 RTT).

Eric and Robin have been actively involved in fundraising and awareness for Rett Syndrome since 2003, when their daughter Abby was diagnosed on her third birthday. They were both members of IRSA and RSRF, and are currently members of IRSF, RSRT and the New Jersey Rett Syndrome Association (NJRSA) of which Robin is the Treasurer and helped create. They are committee members for major fundraising events in both New York and New Jersey, work on several regional projects every year, and published a cookbook to benefit IRSF.

"Once Abby was diagnosed we decided to get involved in every facet of every organization, meet as many families as we could, share ideas, fundraise, raise awareness, create relationships, and help each other through challenging times. We have met some wonderful families, many of which have become good friends with an obvious common bond. By joining the board I plan on expanding upon what we have already started by bringing new ideas and perspectives to a growing organization. My goal is to continue to network and raise funds, and to increase the flow of information and ideas between IRSF and its families."

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## Bill Farnum

Bill Farnum and his wife Beth got involved with IRSF in 2007 when their daughter Ella (7) was diagnosed with Rett. In 2008, with the help of family and friends, they created Casting 4 A Cure, a series of fly fishing and other outdoor events which help raise awareness and funding for critical research and family support. Their goal is to raise \$1M by 2015.

Bill joined Nike, Inc. in 1996 and has worked in various sales and product merchandising roles. His Nike colleagues and friends have been tremendous supporters of Casting 4 A Cure and IRSF, and he enjoys building relationships with other Fortune 500 companies to support the IRSF mission.

The Farnums live in Sherwood, Oregon and also have two sons, Alex (5) and Owen (1) who are always there to help their big sister.

One of his inspirations around fighting thru life's obstacles is Lance Armstrong and Bill utilizes a favorite quote when

referring to the quest to find a cure for Rett Syndrome.

"If children have the ability to ignore all odds and percentages, then maybe we can all learn from them. When you think about it, what other choice is there but to hope? We have two options, medically and emotionally: give up, or Fight Like Hell."

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### Michael Joyce

Michael is a Partner at Richards Barry Joyce & Partners, a Commercial Real Estate Company, based in Boston. The Joyce's became actively involved with RSRF when their middle daughter, Caroline, was diagnosed with Rett Syndrome. The Joyce's co-chair the annual Boston Festival of Food and Wine with Chuck and Paula Curley and are active in sponsoring a Boston area Golf Outing for RSRF as well as assisting with the Massachusetts Chef's Classic event.

Michael is on the advisory board of Providence College President's Council as well as the Providence College Athletic Board. He is also a member of the Greater Boston Real Estate Board.

Michael and Jane are both graduates of Providence College and live in Hingham, MA with their daughters, Brooke, Caroline (RTT) and Allison.

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### Sean Lebson

Sean and his wife, Lisa, became involved with RSRF in 2000 when their eldest child, Jessie Brooke, was diagnosed with Rett Syndrome at the age of 2. Since the diagnosis, Sean and Lisa have been very active supporters of RSRF. They have organized letter writing campaigns, served as committee members for the annual New York City Benefit Dinner and developed teams for the annual tri-state New York Strollathon, which they will co-chair in 2006. In addition to generating a great deal of financial support, they have also provided guidance to parents with newly diagnosed children and have spoken as ambassadors of the organization on a number of occasions.

Sean graduated from the State University of New York at Albany and obtained his Juris Doctor from California Western Law School in San Diego, CA. Sean is a practicing attorney in New York City and lives in Rockland County, NY with his

wife and three children - Jessie (RTT), Cameron and Tristan.

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Karen Nussle

President, Sightline Marketing, Washington, DC

Connection to RS: Friend of IRSA

Karen Nussle has over 17 years of experience in the private, public, political and non-profit sectors. Karen recently became President of Sightline Marketing where she will lead Sightline's internal operations, strategic planning and business development efforts. Over the course of her career, Karen's work has included public relations and advocacy campaigns, corporate and communications strategy development, strategic planning and non-profit management. Prior to joining Sightline, Karen was Senior Vice President at MENTOR/National Mentoring Partnership where she directed public policy, state relations and an extensive internal strategic planning process for this national organization. Before heading into the non-profit arena, Karen was a Managing Director at BKSH & Associates and the firm's parent company Burson-Marsteller, where her client portfolio included Accenture, United Airlines, PBS, the Salvation Army, Chicago Children's Memorial Hospital, and United Cerebral Palsy. Karen also has a broad wealth of political experience, including a long career on Capitol Hill and extensive campaign experience in the State of Iowa. Karen holds an M.A. and B.A. in Communication from the University of Maryland and periodically serves as an adjunct professor at the University of Dubuque in Dubuque, Iowa. Karen, and her husband Jim, live in Manchester, Iowa.

"My three years of work with IRSA were incredibly rewarding in so many ways. I am grateful that I have been able to be a part of such a powerful movement. I am especially excited to be a part of the new IRSF -- seeing the potential we have as a united organization inspires me everyday as a volunteer. The girls with Rett syndrome are a part of me now; there's no going back! I look forward to continuing to work with you to educate the public and policy makers and to find a cure."

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Barry Rinehart

Barry first got involved with Rett syndrome in the spring of 1998 when he wrote and directed the internationally televised documentary, *Silent Angels: The Rett Syndrome Story*, hosted by Julia Roberts. After several years of volunteering, Barry joined the Board of Directors of International Rett Syndrome Association in the Fall of 2003. He became CEO of IRSA in January of 2005. In July of 2007 Barry joined the Board of Directors of the International Rett Syndrome Foundation.

Previously, Barry was a CEO and Creative Director for a successful creative firm in Seattle, Washington. Before that he worked for one of the top litigation-consulting firms in the U.S. as Director of Demonstrative Evidence. Over the years Barry's clients have included: ABC, Boy's and Girl's Club of America, Committee for Children, Compaq, Discovery Communications, Disney, Exxon, Ford, HP, IBM, Kenworth, Mary Kay Cosmetics, Microsoft, NASDAQ, National Geographic, National Multiple Sclerosis Society, Nintendo, Novell, PBS, Procter & Gamble, Real Networks, Starbucks, U.S. West, World Association for Children & Parents, and many more.

"Rett syndrome can be cured. The individuals suffering from Rett syndrome can be helped. .As an IRSF Board Member I want to do whatever I can to make this a reality as quickly as possible."

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Kenna Seiler

Kenna Seiler and her husband, Michael, live in The Woodlands, Texas with their son, Ethan, age nine, and daughter Rachael (RTT) age five. Kenna has practiced law for over eighteen years, and is board certified by the Texas Board of Legal Specialization in Civil Appellate Law. She is a shareholder at Hope & Causey, P.C. and Michael is Judge of the 435th District Court, appointed by Texas Governor Rick Perry. Kenna is a former president of the Montgomery County Bar Association, a former director of Bridgewood Farms, an activity center for adults with special needs, and has served on IRSF's Family Advisory Board. Just days after Rachael's diagnosis in March of 2006 at 22 months old, the Seilers attended the Texas Rett Camp and have been involved in IRSF ever since. Kenna has been part of the Tee it Up for Rett Syndrome golf tournament, the Spending Time, Ending Rett concerts featuring Clint Black, and was the Chair of the First Annual Houston Strollathon in October of 2009.

As the mother of a daughter with Rett syndrome, I can't wait until I get the news that there is a cure for Rett syndrome. I am dedicated to doing whatever it takes to make that happen, not only for my daughter, but for all of the beautiful girls with Rett syndrome, who are my inspiration, and their amazing families. Until that happens, and without diminishing my quest for a cure, it is equally important that we improve the lives of our daughters by providing the most current information to doctors, therapists, educators, and families.

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## Rajat Shah

On May 23, 2008, Rajat and his wife Jenny received the diagnosis that their two-year-old daughter, Sejal Madeline Shah, had Rett syndrome. Rajat and Jenny began researching and learning everything they could about this syndrome to discover how they could better help their daughter and educate the community. Almost a year after the initial diagnosis, the Shahs held a disco-themed "Hustle for a Cure" event in Sejal's honor, which those who attended hope will become an annual affair. Two more fundraisers are planned and in the works. Rajat and Jenny have earmarked all of their fundraising efforts for research to help find a cure.

Rajat has been an attorney for the past 12 years and was the Senior Vice President of Corporate Development and General Counsel for the Seneca Gaming Corporation. Prior to his work at the Seneca Gaming Corporation, Rajat worked for the firm Akin Gump Strauss Hauer & Feld, LLP, where he practiced corporate and securities law. Rajat is currently a member of the Board of Directors of the Women and Children's Hospital of Buffalo Foundation and the Seneca Diabetes Foundation. He was a 2007 Recipient of the 40 under 40 Award from Business First (a Western NY business news publication).

Rajat and his wife Jenny live in Williamsville, New York, with their two beautiful daughters, Simran, age 5, and Sejal (RTT), age 3. Rajat is eager to serve on IRSF's Board: "I am looking forward to helping IRSF achieve its goal of finding a cure for Rett syndrome."

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