

RTS Newsletter

To inform, educate and empower all those whose lives are touched by RTS

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www.rtsplace.org

2023 RTS Live Sharing and Caring Conference - A Major Success for RTS Families!



On the last weekend of this past April, RTS families, board members, invited guests and conference presenters descended on Portland, Maine, in anticipation of the first live RTS Sharing and Sharing Conference in several years. Gone were the days and limits of web-based conferences that held everyone captive for the past three years due to the COVID-19 pandemic. At this year's live conference, RTS families were able to freely interact, catch up with old friends, provide support to each other, share meals and enjoy their time together in person. Children played unreservedly and forged budding relationships and bonds that they may cherish for a lifetime. In the time between and after the formal conference schedule families spent time enjoying the hotel's swimming pool, going out to dinner, and touring Portland's many scenic sites. In many ways, the conference served as a vehicle for RTS families to experience the much-needed social contact and support that has been missing due to the COVID-19 isolation. It was heartwarming to see and be part of something that felt so deeply meaningful and yet so natively organic.

The conference program this year included presentations on various RTS related topics including RTS Management Guidelines and Historical Overview by Lisa Wang, MD, Skin Manifestations in RTS, Moise Levy, MD, and Family Systems and Stress Management, Emil Zakutny, PhD, DSW. In addition, the RTS community was introduced to the emerging importance of patient registries and how to integrate patients, doctors and researchers using these registries. As discussed at the conference, this has significant implication for the future of the RTS Registry in terms of identifying a patient registry that best meets the needs of the RTS community.

At this year's conference, the Sharing and Caring part of the conference was supplemented by a panel comprised of several RTS patients ranging in age from their teens, twenties to adulthood who shared their RTS lived experiences and responded to specific questions from the audience. This resulted in a compelling experience for participants. A post conference anonymous survey revealed one attendee's feelings (see below) about the panel experience, while another shared what they felt was the best part of the conference.

'The panel this year was by far the best part of the conference. Just an open, interactive discussion about RTS, about what they deal with, or other parents deal with in day-to-day life'



RTS Group Panelists



'I always love the time to connect with other families'



RTS Teen Superheroes!!

Letter From the RTS Board Chair

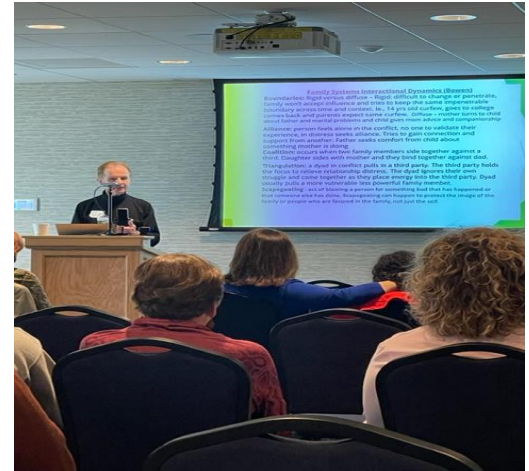
As of this writing, I will be ending my tenure as the RTS board chair at the end of this August. I am grateful to the RTS Board members for their support and for our collaborative work to actualize the mission of the RTS Foundation. To that end, some of the accomplishments of the board include organizing the first post Covid-19 live Sharing and Caring Conference, recruiting several new board members, publishing the quarterly RTS Newsletter and a maintaining a successful yearly fundraising campaign for the past two years to support the RTS Registry and related research conducted by Lisa Wang, MD, at the Texas Children's Hospital.

Of course, much work remains to be done over the course of the next few months and years ahead. This includes increasing RTS awareness via a more a robust social media footprint and presence, expanding fundraising opportunities and resources to support the RTS Registry and related research, and identifying a patient registry that would integrate RTS patients, doctors and researchers in a way that would lead to meaningful treatment options for RTS patients and benefit their families and the larger RTS community.

My departure as the RTS chair is a planned one, allowing the new chair of the board, Staci Hansen, to transition in an organized way. Staci, who has been a board member for the past several years, is an energetic and very talented individual in whom I have the utmost confidence. I believe that with her leadership, and the addition of several new board members, there is a synergistic potential that, I believe, will benefit the RTS Community.

It has been my privilege to serve as the RTS Foundation board chair. While I will continue to be involved with RTS in some capacity, I am grateful to the many people that I have met from the RTS community over the past decade that touched, inspired, and humbled me with their quiet courage and uplifting optimism. Thank you and all the best.

Sincerely,
Emil Zakutny, PhD, DSW



New RTS Board Members



Sylvie Plante hails from Canada, the French province specifically. She is a parent with three children and one of whom, Lea, a beautiful 18-year-old woman, has RTS. Sylvie recently joined the RTS board in the role of the board secretary. Among her many reasons for joining, her lived experiences as a parent of a child with RTS, have strongly influenced her thinking and beliefs about RTS and life in a broader sense. She puts in philosophical terms as she asserts that it is best “with time passing by so quickly, to stop being afraid of RTS, stare it in the face and just deal with whatever comes your way.” She hopes to bring this resilience-based perspective to her work with RTS and the larger RTS community, as well as helping with fundraising efforts and bringing awareness to RTS. We welcome Sylvie to the RTS Foundation and wish her much success in her new role as the board secretary.

Sean McMurray currently lives in sunny Southwest Florida. He is the father of two sons. Sean was diagnosed with RTS as a baby and has lived through some of the common challenges that RTS patients encounter during their life. Sean attended the first RTS conference about 15 years ago. He brings his interest in supporting RTS research, his lived life experience as an RTS patient, as well as twenty plus years of Medical Device Industry experience to his role as a board member. He is particularly eager to participate in strategic efforts to actualize the goals of the RTS Foundation to meet the needs of RTS patients, their families, and the larger community. From the perspective of a father and a patient diagnosed with RTS, he believes that “you can't let RTS define you, it's just something that is a small part of who you are”. We equally welcome Sean to the RTS board and wish him much success in his new role.



2023 “I Love Lucy” RTS Fun Run!

[Sign Up](#)

[Donate](#)

August 13, 2023, is the LAST Day to get your free T-Shirt.

[Sign-Up Today](#)

We have a new design for the 2023 "I Love Lucy" RTS Fun Run shirt! This year's virtual fun run is going to be one for the books. This evening, at dinner, Lucy looks at Jason and I and says, "Is everyone going to do my run again this year?" How can we let her down! I asked her after she said this, "do you know why we have the run?" She responds quickly, "FOR RTS!" She gets it!

This has quickly become an event she looks forward to. We just celebrated Lucy's 5th birthday with a BANG! She is fiercely independent, smart, brave, and always trying to make those around her smile! Let's all repay the favor and put a smile on her face by signing up for this year's run and making it the most successful virtual run yet!



More Memories From the 2023 RTS Sharing and Caring Conference

