

# SRNAmagazine

SIEGEL RARE NEUROIMMUNE ASSOCIATION

Fall 2019



Together we are stronger.  
Together we are **SRNA**

*advocating for those with ADEM, AFM, MOG-Ab disease, NMOSD, ON & TM*

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Follow the Siegel Rare Neuroimmune Association on Facebook ([facebook.com/wearesrna](https://facebook.com/wearesrna)) and Instagram (@wearesrna) and tell your friends and family to do the same. It is a great way to support SRNA and a wonderful way to network with people in our community. Facebook and Instagram are also great ways for us to raise awareness about these disorders and share your experiences.

# A Note from the President

## Together we are stronger

On September 20th, I presented the opening address at the symposium in Columbus, Ohio. I explained why we adopted our name, The Transverse Myelitis Association, and how we then became an advocacy organization for people with Acute Disseminated Encephalomyelitis (ADEM), Acute Flaccid Myelitis (AFM), MOG Antibody-Associated Disease (MOG-Ab disease), Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON), and Transverse Myelitis (TM). We have always been an inclusive and caring community. Our name hasn't been an accurate reflection of who we are and what we do for a very long time. The name needed to change.

Dr. Benjamin Greenberg followed my address and announced the new name for our organization: the Siegel Rare Neuroimmune Association (SRNA). We advocate for people who have rare disorders that impact the central nervous system, and the immune system is involved in various ways in all of them. They cause similar symptoms that are treated in the same ways. There are similarities in the acute therapies to arrest the attacks. There is significant overlap in the long-term therapies used to treat the recurrent disorders. When a physician is trained and develops expertise in the rare neuroimmune disorders, they can and do treat people with all these disorders. Research on any one of these disorders benefits all these disorders. Together we are stronger, because education, support, clinical care and research are more effective by sharing experiences, knowledge, and the power of numbers.

You can watch my and Dr. Greenberg's presentations in our [resource library](#) and on our [Facebook page](#).

As I listened to Dr. Greenberg refer to the organization as the Siegel Rare Neuroimmune Association, I was filled with such strong and complicated emotions. There is no escaping that this honor has come as I've lost Pauline. In my mind and in my work, this organization, my experiences with Pauline, and my love for Pauline have been, and will always be, inextricably bound. Pauline and I were on a truly amazing journey. Her

- Access our library at [srna.ngo/resources](https://srna.ngo/resources)
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getting transverse myelitis and our work for the Association became such a large part of that journey. Speaking to people on the phone or responding to emails was a daily activity. We traveled across the country attending support group meetings and all our education programs. We made visits to the centers of excellence and attended science meetings with other academic centers and organizations. And we made our annual visits to camp. This organization encompassed so much of our lives.

**The Siegel Rare Neuroimmune Association.** It is humbling to think about; and primarily because it wasn't something Pauline and I thought about. We almost never counted coup. We didn't think much about what we accomplished. We thought more about all the work that needed to be done. I am so proud of the work that Jim, Debbie, Paula, Pauline, and the many volunteers over the years accomplished to grow this organization and to create such a positive and supportive culture. I am humbled and so honored that Pauline's and my work will be recognized in the name. I am grateful that Pauline's memory is enshrined in the name and the important work of this organization. Thinking about the name is surreal. Mostly it makes me profoundly sad. It will be impossible for me to do this work without feeling the sadness from my loss.

I'm grateful for my time with Pauline and all of what we shared together. I am grateful that we were able to help people when they most needed someone to care. I am grateful that our work has become a way to bring hope to people who so desperately need a reason to hope.

#### **The Siegel Rare Neuroimmune Association.**

*Humbled. Honored. Grateful. Sad.*

As I listened to Dr. Greenberg describe our work and the meaning underlying our new name, I also had the following thoughts. Given that these disorders are so rare and seem random in their distribution, it is amazing how much we've grown since we established the organization. In the mid-1990s our membership was fewer than 200 people. We are now almost 14,000 people from more than 100 countries around the world.

When most of our members were diagnosed with their disorder, there was a Transverse Myelitis Association. They were able to get onto the internet or make a phone call to our organization to get the information they needed to find aggressive acute care. They were able to learn something about their disorder. Many were able to find a doctor who had some understanding of their diagnosis. They were able to find a rehabilitation center that provided aggressive therapy. They found support. Not everyone did; that represents some of the important work in front of us. But many did and do.

I wondered whether people think about what their lives would have been like or what their lives would be like today without SRNA? Why would they? Pauline

and I went through this experience without any of what the organization offers today, so I do think about it.

All of what we offer is critical to the experience a person is going to have when they are diagnosed. Their diagnosis will impact their entire family, and we focus our support on the entire family. We can't currently change that this is going to happen to a person. We have no idea what to look for in a healthy population to figure out who is at risk for any one of these disorders. What we can do is focus on providing a better outcome and a better quality of life for a person who gets one of these rare disorders. Our hope is that one day, we would be able to understand enough about the genetics and the environmental triggers to determine who is at risk and find solutions to mitigate against those risks. That will not happen anytime soon.

If you received plasma exchange, you likely got this treatment because the physicians in our community have gained enough experience to be confident in its effectiveness. They are disseminating this experience to their colleagues. PLEX hasn't proliferated as an acute treatment from tons of research and clinical trials. It has become more widespread from advocacy and physician education in **our community**.

We offer excellent education opportunities to our members. We've helped people become more effective advocates for their medical care. We're educating physicians and researchers to increase the possibility that people from our community will be cared for by an expert and that research will be accelerated. We offer the support people need to get through such a complicated and challenging experience; through our support groups, our awareness events and our family camps.

What would life be like without an SRNA. It would suck. I know. Pauline and I lived in that life. Maureen did. Jim did. Debbie did. Paula did. They'd tell you. It was frightening and isolating.

Do people take for granted that we exist? I'm sure they do, because they've not known a life without us. Many people probably don't think about us at all unless they receive one of our mailings or an email, if they open it.

Whether you are involved in many of our programs and know of SRNA from our symposia, newsletters, podcasts, blogs, support groups, our website, our social media presence and our camps or if you never think about who we are or what we do, we're working on your behalf every single day, and you ultimately benefit from this work.

We're educating physicians and researchers. We're supporting and growing our network of rare neuroimmune centers. We're advocating on your behalf with other organizations and government agencies, we're working with companies to encourage research in these disorders. We're working to raise awareness in the general population. Whether you think about it or not, you significantly benefit from this work.

I don't know how you find hope in your life when you are faced with daily challenges that come with one of these disorders. Some people find hope in their faith. Some can find it in their families and communities. What I learned from our members and primarily from Pauline was that hope came from research. Pauline wanted to get better. She wanted to feel better. The path to a better quality of life for Pauline was research.

The Siegel Rare Neuroimmune Association is about making connections, caring about our community and finding a cure. Connect. Care. Cure. We are all about hope.

It was nothing short of a miracle that a small group of volunteers could create and keep an all-volunteer organization moving forward for almost 20 years.

Our future isn't going to depend on miracles. Our continued existence, our work, what we are able to accomplish will depend on all of our efforts to make a difference. We need to get everyone involved. Attend support group meetings and awareness events. Start a support group and create a new awareness event in your community. Become a positive and informed mentor for someone in your community or on social media who needs support. Become a participant in our registry and other research opportunities.

**And help us raise money!** It would be difficult to imagine that there is anything that has happened that has created a greater impact on your daily life than being diagnosed with one of these disorders. We are competing for good cause dollars with many important and worthy organizations. They all deserve our support. What I am asking you to do is consider how rare our disorders are, how small our base of support is to keep our work going, and where that support is going to come from if it doesn't come from the people who have these disorders. If that support does

not come from you, it doesn't come at all. Who else cares? Who else even knows about us? You didn't until you were diagnosed.

Why do I care? The work I did for all these years was motivated by Pauline ... from beginning to end. I still do the work and I still care, because of Pauline. This is her legacy. Having transverse myelitis changed her life; it changed everything about her life. All of what she wanted for a better life I also wanted for her, and I wanted to do my best to make it happen. I do all that I can every day to continue to make a difference. I donate to SRNA all that I can afford. I make SRNA my priority, and this organization receives the majority of my good cause dollars.

If you can afford to give a lot, I implore you to do so. What SRNA does and how much we can do depends entirely on our resources. Our resources depend entirely on you. With your help, we can get more research done, train more clinicians and researchers, and offer more extensive support and education. If you can't afford to donate a lot, do what you can. We are grateful for whatever you can do. We appreciate all the donations we receive regardless of the amount.

Please ask your family and friends to make donations, as well. They know how your life has been impacted by your disorder. Often, they want to help, but they don't know how to offer it. Please give them a way. You have people in your lives who can make a significant difference. Please give them a reason and a purpose for making that difference in your life. You will never know what they can do unless you ask. Please ask.

Thank you so much for helping us to help you!

Please take care of yourselves and each other.

*Sandy*

# Expanding Partnerships to Better Serve our Community

*By Sandy Hanebrink, Executive Director of Touch the Future Inc.*

**Touch the Future Inc. (TTF) and the Siegel Rare Neuroimmune Association (SRNA—formerly known as the TMA) are excited to work together to provide technology, resources and services to support individuals, families, and providers in the rare neuroimmune disorder community.**

It is my honor to introduce you to my organization, [Touch the Future Inc.](https://touchthefuture.us) We are a 501(c) 3, nonprofit organization, whose mission is to create accessible, inclusive and environmentally sustainable communities that increase opportunities for independence, health and improved quality of life for individuals who are disabled, seniors, disabled Veterans, or from disadvantaged communities. We are committed to the use of technology and our programs and services to assist individuals to successfully meet life goals. We strive to ensure that technology is accessible and affordable to all. Our vision is a technologically connected world that is healthy, accessible, and inclusive, providing equal opportunities and maximum independence for all. We provide access to assistive technology, funding and fundraising support, continuing education, ADA and accessibility consulting, and training and resources to help individuals with disabilities, their care partners, and providers to network and understand processes, laws, resources, and technology available to improve lives. We are a link to independent living and Touch the Future of lives every day.

● Learn more about Touch the Future by going to [touchthefuture.us](https://touchthefuture.us)

I am Sandy Hanebrink, OTR/L, CLP, FAOTA, the Executive Director of Touch the Future. I have had Transverse Myelitis since 1987, though I had many different diagnoses bestowed upon me until I met Dr. Doug Kerr at Johns Hopkins. I am sometimes called “the other Sandy” and am honored to have accepted calls and emails from Sandy Siegel as an active resource for the Siegel Rare Neuroimmune Association (SRNA), formerly the Transverse Myelitis Association, for almost twenty-five years. I am an occupational therapist and have developed a practice niche in advocacy, assistive technology, and networking individuals with disabilities and service providers to the necessary resources and funding to achieve individual life goals. I have worked in school systems, for local and state governments, in rehabilitation hospitals, for the Social Security Administration and in private and community-based practice. I have multiple presentations and publications from the local to international levels, including topics on effectively educating and employing individuals with disabilities, reasonable accommodations, disability laws, disabled sports, and assistive technology. I am a Paralympian and have been a member of Team USA for swimming, athletics, and wheelchair basketball. I continue to hold four American records and three World records and have a Gold Medal from the PanAm Games, Silver medal from the World Championships, and Bronze Medal from the Paralympics. I have received many awards and recognitions for my work with the most recent being the Roster of Fellow from the American Occupational Therapy Association for Excellence in Technology, Disability Rights & Inclusion.



So enough about who Touch the Future is and who I am. What I am truly excited about is how TTF and SRNA can work together to provide more resources, technology, and opportunities for the rare neuroimmune community; how we can help promote each other and expand our networks; and how you will have access to the years of experience and networking that my organization and I bring to the partnership, increasing opportunities for individuals to gain access to needed assistive technology to improve independence, and helping individuals and their care partners and providers to learn what supports and resources are available and how to navigate the systems. We hope to develop tools and resources specific to the rare neuroimmune community, to help individuals navigate healthcare and social support systems globally. We plan to work together to ensure events are more inclusive and accessible to all. We hope to expand continuing education opportunities for our healthcare partners while expanding the knowledge base and population of providers available for our community. And we hope to engage more members of our community to expand opportunities, networking capabilities and build more partnerships to make our community stronger. Together we are stronger and together we can help the SRNA achieve its mission to connect people, care for those who are affected, and to further our work of finding a cure and ending rare neuroimmune disorders for good.

**“Sandy has been a member of our Association for a long time. Her training, experience and generosity have made her a wonderful resource for our community. We are excited to establish this relationship with her organization. Sandy will continue to provide valuable services and opportunities for the people in our membership.”**

Sandy Siegel, President of the Siegel Rare Neuroimmune Association

# Reflections on the 2019 Quality of Life Family Camp

*By Rebecca Whitney, Pediatric Programs Manager*

**Another steamy southern summer day greeted 34 families and numerous TMA, now SRNA, volunteers at the Center for Courageous Kids in Scottsville, KY, on July 27, 2019. The families who attended represent our community, as their children have been diagnosed with a rare neuroimmune disorder. We gathered for five days and created new connections, caught up with friends from previous years, learned from and supported one another, and experienced joy as a community. For many, it was the last summer vacation before school started and a chance to catch-up with old friends. For others, it was a new opportunity to see what this camp is all about after an overwhelming period of significant life changes their family never asked to experience.**

Our 2019 camp brought together families diagnosed with each of the disorders we advocate for. Approximately half of our families previously attended camp, and the other half were new to the experience. It's always incredible to have so many families wish to return to camp. It's a testament to the power of coming together, and the positive experience camp provides for a family. It's powerful to see the changes in children, their siblings, and parents over the years, too. A few years ago, a young boy and his family attended for the first time. I recall meeting and speaking with them, very quiet and reserved, uncertain of this new territory they found themselves in. Their young son, still clearly recovering from his acute event, was unsure of what to think about this unique experience. They've returned each year since, and the transformation and recovery of the family has been apparent each year. Their son's visible scars are healing. This year, he moved confidently, and with a strength none of us knew he might have after his diagnosis. His family was confident in his abilities; they showed tender care for him yet also allowed him to experience camp and the various activities as he continued to learn how to make his body work for him. They displayed strength in their determination to learn about these disorders and advocate for him and the other children with these diagnoses.

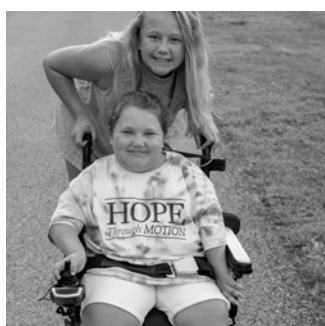
The number of new families this year at camp reminds us that these diagnoses continue to disrupt families' lives. It reminds us we must continue to support our pediatric members, to show them they're not alone, so their families know they're not alone. A child deserves to experience the joys of childhood without the additional concerns and fears these diagnoses too often represent. Before camp, in speaking with one of the parents, I learned of her daughter's most recent camp experience since her diagnosis. She was anxious about attending ours but glad she could do so with her family. She had previously participated in another camp, and a worsening of her symptoms was ignored. As a result, her week ended early with a trip to the emergency room. It left fear in her

that others wouldn't understand or take her seriously if she had similar concerns while attending our camp. I did my best to reassure her parent that there would be many clinicians among the families and kids, many who know and understand these disorders. She wasn't going to be alone or ignored. I'll never forget when this young lady was amazed and so excited after a particularly fun evening and said, *"This is the best week EVER!"* It was a moment of affirmation for me that our camp is a necessary experience.

Our camp represents a fantastic opportunity for families and children to meet and spend time with others with these diagnoses. It's an opportunity to connect with those who understand; to see someone who walks with a similar, unusual gait pattern; to see others use the same equipment; to see they're not the only one with visible scars from surgeries. It's a chance to connect with just a look from another that confirms they know the silent pain of an *"invisible disability"* - a look between peers, parents, siblings, that says, *"I've got you."* There's power in connecting through our shared experiences, and although these experiences can be horrifying, we take comfort in knowing we're not alone on this road.

In spite of being at camp because of a medical diagnosis, the kids and their families need to know they aren't their diagnosis. Although it is an integral part of their identity, it's not the only thing that





a child or family represents, knows, feels, or dreams. They're kids, young adults, families with goals, ideas, and desires, just like any other. The unfortunate truth is that for many of our families, the diagnosis has interrupted, challenged, changed, or made the joy of life seem unattainable at times. Camp exists to remind each of us that even in the dark times, in spite of the challenges and difficulties these diagnoses bring upon our families, joy can still exist. At this year's camp, we saw it in the huge smiles when everyone on the dock was surrounding and cheering on the one reeling in "the big one," or when the child who wasn't able to leave their power chair rode a horse for the first time. My heart experienced emotions words fail to describe. To see conversations and relationships develop between parents, the kids, our medical professionals, and the fantastic CCK counselors was profound. The connections were real, and the noise level during meals proved the excitement only continued to escalate as we finished the camp session. Questions

and conversations starting in the evenings or during siesta and educational sessions continued to facilitate connections between all participants of the camp, solidifying us as a family and community. The excitement culminated on one of the days with messy games! It's an evening that reminded us camp is about being silly, having fun, and whatever diagnosis one may be living with, you could participate! And believe me, it was an event not to miss!

When you thought it couldn't get any better, the reflection of the evening lights bounced off the shower from the fire truck, shining on so many amazing people, laughing, dancing, washing their mess and cares away; the reminder that joy still exists descended on us.

Our week didn't end with messy games, but instead, we continued our fun, learning, and connections right through to stage night and fireworks the night before we had to all say goodbye and head back to our homes. We hope that upon returning

home, everyone shared with their extended family, friends, and clinicians all they did and learned at camp. From stories of other families "just like us", to how you make horse hooves sparkle, the ways we hope the latest research endeavors may impact our children's futures, or how the best way to hook a catfish is with hotdogs; sharing about camp and the powerful ways it has and continues to impact our community, our families, and children, is vital to seeing its continued success.

Camp is exhausting and yet rejuvenating at the same time. It takes an immense amount of time, energy, and financial resources for it to come to fruition each year. It doesn't happen without the support of our community through donations and volunteers. We're fortunate to have tremendous young people who've been previous camp attendees, as well as students touched by their own sibling's diagnosis, who want to give back and attend as volunteers. We're blessed to have a fantastic roster of medical, educational,

and scientific experts who take time away from their families and work to spend their days and nights with us. They answer our questions, share their knowledge, experience, and genuinely listen to and take in our deeply personal experiences and concerns. Our partnership with CCK is a longtime valued relationship, and their willingness to continue to work with us, allowing us to offer our unique programming inside of theirs, is invaluable. Their grounds are beautiful, their counselors welcoming, and their staff is top-notch.

2019 camp wouldn't be possible without the generous support of the Christopher & Dana Reeve Foundation Quality of Life Grant. They continue to uplift families and children through their support and resources; we are so grateful they chose our program as a way to contribute to the greater spinal cord injury community! The Roles Family Foundation and The Rachel Williams Foundation grants allowed us to support travel costs for families needing financial assistance to and from camp.

The first thing I think of when I think of camp (and as part of my work, it is every day), I think of Sandy and Pauline Siegel. I didn't

know them before my own family's very first year of camp in 2012. The vision of a program they had so many years ago profoundly changed my life. They worked tirelessly to see that camp was a possibility each year. Camp wouldn't be an integral part of our organization, our community, our future, our children's futures, without them. Although Pauline is no longer with us, and we miss her so intensely, her spirit, her smile, and her overwhelming love for the kids of this community perpetuate through camp. And, I'd be remiss if I didn't say that I thought of her every time I dug in the coolers after lunch or dinner at camp, looking for the elusive fudge bar or ice cream sandwich. I think she would've fought me for the last one! It's a privilege and an honor as a member of this community to be able to plan our 2020 Siegel Rare Neuroimmune Association Quality of Life Family Camp. The new name encompasses a legacy of a couple who value joy, family, community, and inclusion when it's needed most. The 2020 SRNA Quality of Life Family Camp will take place on July 24-28, 2020. We hope you'll consider supporting camp and our families, spreading the word to others who may benefit from the program, or joining us as an attendee.

# SRNA Receives Quality of Life Grant from Christopher & Dana Reeve Foundation

**The Siegel Rare Neuroimmune Association (SRNA — Formerly Known as the Transverse Myelitis Association) is proud to announce that it has been awarded \$25,000 as part of the Christopher & Dana Reeve Foundation National Paralysis Resource Center (PRC) High Impact Priority Quality of Life Grants and Direct Effect grants cycles.**

Seven High Impact Grants totaling \$232,266 and 73 Direct Effect Quality of Life Grants totaling \$1,244,263 were awarded. The Quality of Life Grants Program supports nonprofit organizations that empower individuals living with paralysis. Since the Quality of Life Grants Program's inception, 3,153 grants totaling over \$26 million have been awarded. Funding for these new cycles of grants were made possible through a cooperative agreement with the Administration for Community Living (ACL grant #90PRRC0002-01-01).

The Reeve Foundation National Paralysis Resource Center has a number of grant programs under the Quality of Life program awarding grants in different category areas, varying in different amounts. The High Impact Priority Quality of Life Grants fund projects in the following areas: Transportation, Respite/Caregiving, and Disaster Response, Nursing Home Transition, and Employment, while the Direct Effect Grants support a wide range of short-to mid-term projects and activities that will clearly impact individuals living with paralysis and their families.

"There are several components that go into these projects," said Mark Bogosian, Director, Quality of Life Grants Program. "If we can provide programmatic and other financial supports, even in the short term with the Direct Effect grants, these organizations can now focus on executing their mission, leading to greater success, expansion, and sustainability."



The Reeve Foundation funded a wide variety of projects from employment programs to accessible playground projects and adaptive sports programs.

The Siegel Rare Neuroimmune Association used the grant for costs and expenses associated with the 2019 Quality of Life Family Camp, held in Scottsville, KY, at the Center for Courageous Kids, July 27 through July 31, 2019.

SRNA is honored and so grateful to receive the grant from the Reeve Foundation! Thank you to the foundation for your generous support and assistance which allows us to provide a unique, educational, and quality experience to our children and families!

## About the Reeve Foundation

The Christopher & Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research and improving the quality of life for people living with paralysis through grants, information, and advocacy. The Paralysis Resource Center (PRC) is the support side of the Reeve Foundation's twin missions to provide "Today's Care" and to strive for "Tomorrow's Cure" and offers a free, comprehensive, national source of informational support for individuals living with paralysis and their caregivers. We meet all 20 of the Better Business Bureau's standards for charity accountability and hold the BBB's Charity Seal. For more information, please visit [ChristopherReeve.org](http://ChristopherReeve.org) or call 800-539-7309.

## Contact

Rebecca Whitney  
Pediatric Programs Manager  
SRNA  
(855) 380-3330 ext. 5  
[rwhitney@wearesrna.org](mailto:rwhitney@wearesrna.org)

Anna Chamberlain  
(973) 379-2690 ext. 7133  
[media@ChristopherReeve.org](mailto:media@ChristopherReeve.org)



# The Patient Experience with Transverse Myelitis: a Book Review

*By Allen Rucker*

Allen Rucker grew up in Bartlesville, Oklahoma and has degrees from Washington University, St Louis, the University of Michigan, and Stanford. In the 1970's, he co-founded the pioneering video group, TVTV, winning the Columbia-duPont Journalism Award. In the 80's he wrote sketch comedy with Martin Mull, Harry Shearer, Fred Willard, and others, winning the WGA Annual Award for Comedy and two CableAce Awards. In 1996, he became paralyzed from the waist down from transverse myelitis. Post-paralysis, he has written or co-written eleven books, including three books on "The Sopranos," one of which was a #1 New York Times bestseller, and a memoir of life after TM, "The Best Seat in The House." He is chair of the WGA Writers with Disabilities Committee and the annual Media Access Awards and writes regularly for New Mobility magazine and the Christopher Reeve Foundation website.

Sandy Siegel is a force of nature. I have known him for almost twenty-three years and am continually blown away by the energy, commitment, and compassion he's freely given to people with transverse myelitis and associated disorders. Like many of you, Sandy was the first person I talked to after my own injury who knew more than a few medical-school facts about TM. When you first speak to Sandy, you intuitively grasp the mantra often repeated in this expansive and definitive book on living with this weird and mysterious disorder – you are not alone.

Sandy claims early on in the book that *"no one in the world has spoken to more people with TM"* than he has. Without a doubt. He then explains why. *"This is likely to be the case until the end of time, as it would be difficult to imagine another human being stupid enough to post their home phone number all over the internet."*

Sandy's *"anthropological"* overview of TM – he's not a doctor but knows this specialty

cold from a laymen's point of view – begins and ends with his late wife, Pauline, who first contracted TM in 1994. She taught him, as have many other sufferers, what he knows about living with rare neuroimmune disorders. This book is grounded in the myriad of personal, and often personally told, stories and the myriad of approaches or solutions to the inevitable presence of pain, loss of bodily function, self-doubt, and social anxiety associated with TM, not to mention how to deal with pesky matters like incontinence and airplane travel. Here Sandy, more than in any other book I know of on the subject, went to the source – actual TM'ers and their caregivers and friends.

The book is long, goodness knows, but never tedious or dry. Sandy can tell and retell stories and they are not only full of both the emotional and medical components of TM, they are infused with the main thing that makes this book great – Sandy's voice. Throughout, Sandy is kind, patient, and non-judgmental in describing one's adjustment to TM, even for those who push people away and never transcend the bitterness and loss.

Sandy is the rabbi of transverse myelitis — there to help and give comfort and not to profit personally. Answering the phone at 11:30 on a Thursday night to listen to and advise someone newly faced with TM is not a pathway to personal aggrandizement or even a decent night's sleep.

Not that he hasn't faced his own dark moments of guilt and inadequacy. Speaking as husband and caregiver stunned by his wife's misfortune, he asks: *"How does one experience an intense tragedy and life-changing event without running headlong into some self-doubt? I have had significant questions about my character throughout this entire experience with Pauline's illness. I have experienced significant inner struggle between who I am and the person I would like to be...."*

As he delineates the reality of living with one of these disorders, Sandy is sympathetic but never less than blunt about the often-ugly consequences. He occasionally writes in sentences so direct and unsentimental that they almost read as aphorisms. Here is a sampling:

*“Pain, depression, and fatigue can conquer the soul of the strongest of human beings.”*

*“There is nothing more demoralizing for a person with transverse myelitis than to have regular bowel and bladder accidents.”*

*“TM complicates a good marriage. TM is going to obliterate a bad marriage.”*

*“Nerve pain is the game changer with TM... For people who are paralyzed and have nerve pain, paralysis is the least of their burdens.”*

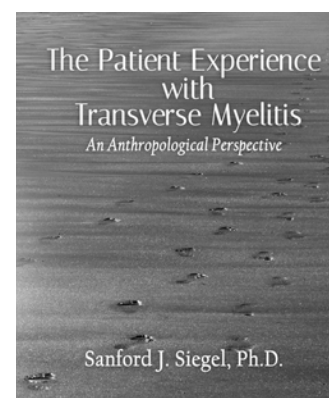
Sandy’s role throughout Pauline’s long illness was that of caregiver and despite his doubts, he was a stellar one. Very few caregivers know as much about the most intimate details of life with TM – spasticity, bowel/bladder failure, sexual dysfunction, infections, UTI’s, thoughts of suicide, the awful, often silent presence of fatigue – and what he doesn’t know, he has found some remarkable people to tell their own tales.

Some of these stories are heartbreaking. I will never forget Elisa Holt’s account of discovering that her first-born son, Noah, had contracted, at six months of age, Acute Flaccid Myelitis (AFM). In the blink of an eye, Noah went from healthy to paralyzed from the waist down. In facing what she calls “a parent’s worst nightmare; a nightmare I didn’t even know existed,” Elisa and her husband guide their little boy through what will surely be years of intense physical therapy in their collective effort to “take back AFM.” Her parting advice to any parent in the same situation: “You’ll make it through the wilderness.”

Sandy knows a hundred of such stories of struggle and courage and his empathy seems to know no bounds. One of my favorite passages in the whole book involves those with TM, even if they are physically impaired, who have many ongoing side effects that others can’t easily see. Sandy offers up his sage if acerbic advice: “*Perhaps people with TM should think about wearing a sign with print that says, ‘I haven’t peed in eight years. My feet and legs and butt are in so much burning pain that I would scream all day long if I were allowed...my fatigue has me so totally exhausted that I need a nap ten minutes after I wake up. I have transverse myelitis...and because you can’t see the symptoms... doesn’t give you a pass to make judgements about me in any way.’*”

I could go on picking out sound bites of hard facts and insights into the mindset of someone with TM and still feel I’ve failed to convey the scope, depth, and magnanimous spirit of this definitive “brain dump,” as Sandy calls it. As it began with Pauline, so it ends with Pauline. She is his lodestar on this journey. Without Pauline’s illness and her openness about it, and Sandy’s remarkable tenacity and passion, there probably would never have been a Transverse Myelitis Association – now called Siegel Rare Neuroimmune Association – and hundreds of thousands of sufferers, myself included, would be left not knowing how to deal with the next day, or the day after, how to find expert medical help, or how to discover a community of people who know exactly what you’re talking about. Sandy has helped build a public edifice of knowledge and goodwill that will far outlive him, and he has now written a book full of the wisdom of a lifetime dealing with TM.

We all owe him our supreme gratitude.



- You can purchase a copy of *The Patient Experience with Transverse Myelitis* on [amazon.com](https://www.amazon.com). Both paperback (\$18) and Kindle (\$2.85) versions are available. The book is self-published.



# Up & Down

*By Sarah Todd Hammer and Jennifer Starzec*

We, Sarah Todd Hammer and Jennifer Starzec, have been writing since 2012, and it has brought us closer together. From Facetiming for three to five hours at a time to write, to staying up until two in the morning putting the final touches on our third book, sharing our stories with the world has provided us with unforgettable memories. We're seventeen and twenty-one years old, and when we started the *5k, Ballet* series, we were only ten and fourteen years old. Every book we publish is different, but each one pertains to our diagnoses and what comes along with them. When we began writing our first book, we had no idea how much our series would grow or how much of an impact it would have on others (and ourselves!). Several people—patients, parents of patients, and caregivers alike—have come to us and shared how much our books have helped them get through rough times, which makes both of us incredibly happy. One of our main goals when we first started the series was to help spread positivity and encourage others, because we know dealing with life-altering disorders such as rare neuroimmune disorders is extremely difficult, and it has become clear to us that we've succeeded in accomplishing that goal!

Six years ago, we published our first book, *5k, Ballet, and a Spinal Cord Injury*. Three years ago, we published our second book, *Determination*. And now, three years later, we've completed the *5k, Ballet* trilogy with the publication of *Up and Down*! We'd always known we wanted to make the *5k, Ballet* series a trilogy, and it is so incredibly rewarding to have accomplished that.

Our lives were changed when we were only eight and thirteen years old through diagnoses of acute flaccid myelitis (AFM) and transverse myelitis (TM), but we were both determined to dance and run again as we struggled to cope with our new disabilities. As we got closer to one another and became great friends, we found a lot of support and comfort in our friendship. Every time we had any sort of hardship, we knew we could always talk to each other.

Just like our friendship has helped us get through the difficult times, so has music. We've both found solace in many different forms of music during the "low notes" of our lives with AFM and TM, which has changed how we view our struggles. It's comforting to know that, no matter how many times life gives us those "low notes," there are more "high notes" to come. We've learned throughout these years that diagnoses of AFM and TM always come with ups and downs, and both of us had a lot of ups and downs during the time period of our newest book—2014 to 2017—hence the title, "*Up and Down*." We wanted to show that the "downs" and "low notes" are necessary parts of life, but there are more joyful times to come as well.







## The Process

Since we started writing in 2012, our skills have grown, and our writing has become more mature. In *5k, Ballet, and a Spinal Cord Injury*, the beginning of our stories can be seen through the lens of an elementary schooler and middle schooler. Our stories began when we were young, and as we lived with our disabilities for longer, the experiences we had helped us grow and mature over the course of the series. Because we've aged six years since we began the series, *Up and Down* demonstrates our most mature writing and experiences as young adults as compared to our other two books. Being older presents a unique set of challenges of living with a disability, because navigating through certain situations as a young adult is a challenge for everyone—and even more so when a disability is present on top of it.

Writing is an excellent way for us to share our emotions concerning our disabilities, and we've found that it's cathartic and rejuvenating. It allows us to present ourselves to the world and make an impact in others' lives through storytelling and charity. And, through writing, we've grown closer, and we hope to continue writing together in the future! Although the *5k, Ballet* trilogy is over, we know for sure that we'll continue to share our stories through writing, and it will definitely be exciting to see how many more books we publish! Until our next book release, we encourage our readers to keep their chins up high, follow their dreams, and never give up no matter what life throws at them!



- “*5k, Ballet, and a Spinal Cord Injury*”, “*Determination*”, and “*Up and Down*” are available for purchase on [amazon.com](https://www.amazon.com) and [lulu.com](https://www.lulu.com), or through the girls' website, [5kballet.com](https://www.5kballet.com)
- Continue to follow their stories at [5kballet.com](https://www.5kballet.com)
- Follow them on Instagram  
@sarahtoddhammer  
@jenstarzec









# Stronger Together

To commemorate our 25th Anniversary and the progress we've made together, we have changed our name, effective November 1, 2019. We are now called the **Siegel Rare Neuroimmune Association (SRNA)** in honor of our founders, Pauline and Sandy Siegel, and in honor of all the people we serve.

We've continuously advocated for those affected by rare neuroimmune disorders of the central nervous system. We recognize that our name needs to be a reflection of all that we are and *all those we represent*. That is why, in solidarity with all those we serve, we're taking off the nametag 'Transverse Myelitis Association' and becoming the **Siegel Rare Neuroimmune Association (SRNA)**.

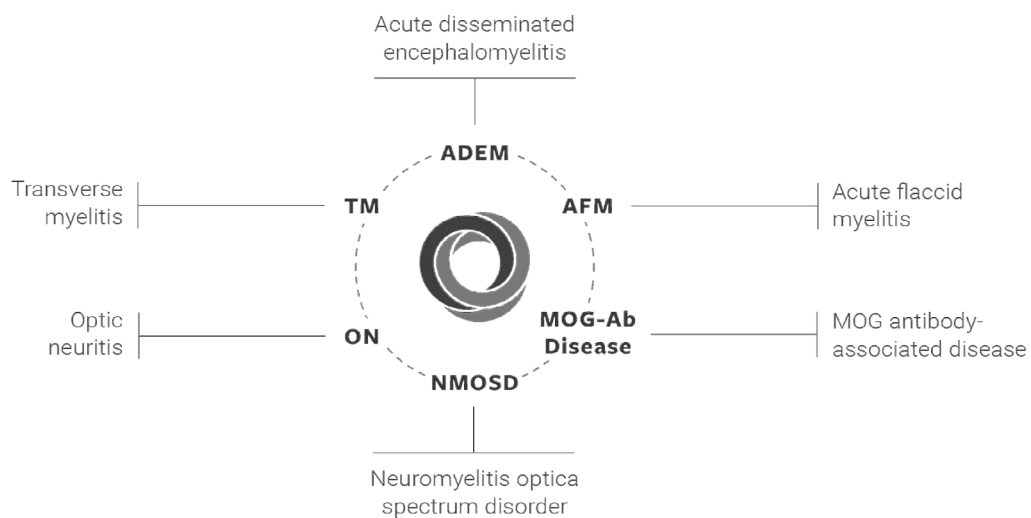
We're still the same organization, on a mission to **connect** people, **care** for those who are affected, and to further our work of finding a **cure** and ending rare neuroimmune disorders for good; just like we have for the past 25 years. That doesn't change. We know we need to always keep learning, and we believe in the power of *togetherness*. Everyone, everywhere, can change the future with us.





## We are all connected through shared experiences

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**When we learn about one, we learn about them all.**

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# We asked members of our community to share their thoughts on our new name and our message of “stronger together.”

**“There is comfort and encouragement in togetherness. It builds strength and motivation.”**

Amanda Stuckey, TM

**“A rare neuroimmune disease is not something to take on alone. SRNA has connected our family with other families facing the same challenges, as well as support and medical professionals that we otherwise may not have found. Together we can further research on these conditions and have a better chance of finding treatments and cures. We can also support each other during a family’s most difficult times.”**

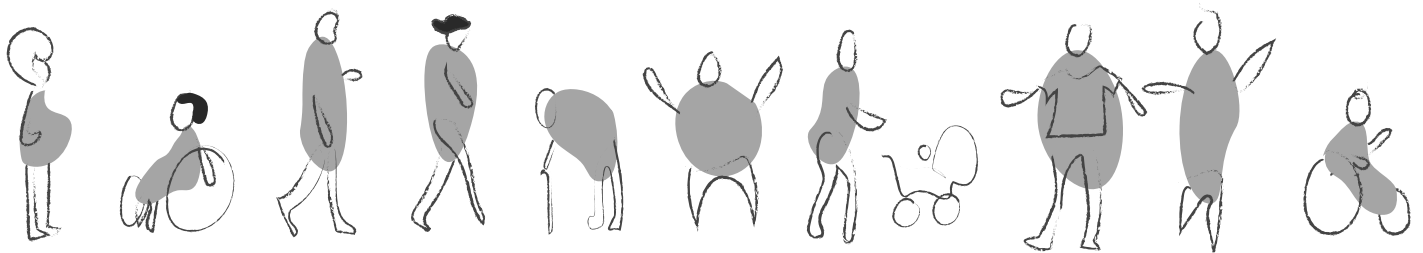
Jason and Rebecca Clark, Parents of Addison Clark, MOG-Ab disease

**“We are stronger together because we need as many people to come together for one cause so we can get our voices heard, so we can advocate for all of us that have a rare neuroimmune disorder and not just one thing. We can do this. We will do this! Stronger together.”**

Amy Shultz, TM

**“Meeting fellow rare neuroimmune diagnosed patients is heartwarming and encouraging in the healing process.”**

Robin Kaminski, NMOSD





“Our particular disease, ADEM, is so rare that to be able to be a part of an organization that brings together doctors, nurses, therapists, and other families is remarkable. We are honored to be a part of the SRNA family. We were not put on this earth to be alone but to join together with others and help each other. By doing so, we are a group of individuals, alone we are weak, but when we are together — we are stronger together!”

Maxwell Clark, ADEM

“Stronger Together because “it takes a village””

Kimberly Mazur, mother of Jordan,  
Longitudinally Extensive TM

“As a parent of a child with Acute Flaccid Myelitis, the support and resources the Transverse Myelitis Association has provided to us over the years have been invaluable—and this name change is an outward sign of their commitment to all rare neuroimmune diseases! We’re so grateful for SRNA and their ongoing fight for those affected by AFM.”

Rachel Scott, mother of Braden, AFM

“All of these diagnoses are so rare and having a group of people who have had similar experiences is invaluable.”

Thomas Griffith, MOG-Ab disease

We are so grateful and humbled by the support of our community. We could not accomplish our work without your generosity and care. SRNA is excited to take this next step in our journey with you, and we hope that you are excited too! If you would like to tell us why you believe we are stronger together, please email us at [info@wearesrna.org](mailto:info@wearesrna.org).

# Inspiration on the National Mall

*By Julie Lefelar*

**Tanisha Willis is a determined woman. She also has Neuromyelitis Optica (NMO) and Lupus. Don't be fooled by the notion that she has two debilitating autoimmune disorders; she inspires us all. When she came to me and Cynthia Albright to organize a walk on the National Mall in Washington D.C., we both were a little hesitant. We were worried that we would not be able to pull it off. Little did we know that Tanisha knew better. It was a fabulous idea.**

This past September, with the help of TMA, now SRNA, we got up very early in the morning and traveled to the beautiful and historic Constitution Gardens, surrounded by so many of our nation's coveted landmarks. It was the perfect place to gather with our peers in this journey with rare neuroimmune disorders. We were blessed with a sunny, perfectly temperate day, a tranquil pond full of ducks and geese cutting through the glass-like water, dipping their bills rhythmically almost in unison, and the majestic Washington Monument rising above the trees to remind us that we were, in fact, in one of the most photographed areas in the U.S. There was a wonderful turnout of people of all ages, some with their furry friends in tow, ready to use their voices and let everyone know that they stand up against the unwelcome visitor who has invaded their lives. With everyone happy and thankful for the medical professionals who help them live as normally as they can, the energy was remarkable.

Our morning started with some words of inspiration by Tanisha, then transitioned to Jeremy Bennett from SRNA who always provides us with the latest SRNA news and lets us know that what we do as volunteers is of immense importance. Our special guest speaker and favorite rock-star doctor, Dr. Michael Levy, who came all the way from Boston, gave a fantastic speech that let us know that the medical community is fighting very hard on our behalf. Then our musical guests, the Dream Team, gave the whole event a reggae vibe as we started our walk. Naturally, in her usual form, Tanisha recorded the walk on her phone as she experienced it live, streaming online for all to see with commentary that was equally fun. We had the promise of a big basket of cookies as motivation to show the best spirit and our guests did not disappoint. We had so much fun passing out door prizes as well and everyone, regardless of whether they won a prize, left much richer with new connections and friends, some from as far as Canada!

We can't thank our sponsors enough: The MOG Project who sponsored our walk by holding a huge t-shirt drive, Tanisha's church, The Miracle Center of Faith, Missionary Baptist Church, who reached deeply into their pockets to make sure this event was a huge success, as well as Merle Norman of Olney, Maryland for the fantastic door prizes. We had such great volunteers as well, and we thank the families and friends of the organizers, as well as those from SRNA who have supported us consistently. We walked away thinking that we can't wait to do it again. It was indeed a good day.







# SRNA Walk-Run-N-Roll Recap

## 2019 Illinois Walk-Run-N-Roll

A week of rain threatened to derail the 2019 Illinois Walk-Run-N-Roll. Willow Stream Park became aptly named as parts of it became flooded. Fortunately, the sun came out, the ground dried up, and more than 150 participants enjoyed a day of awareness, activities, and remembrance.

As people arrived, they were greeted by the energetic sounds of DJ T-Y, who provided the soundtrack for the event. Stories of those diagnosed with rare neuroimmune disorders hung from clotheslines stretched under the pavilion. Emcee Bill Shaner kept the crowd informed by reading off statistics about each disorder. The Jesse White Tumblers, who attended last year's walk, entertained once again with their amazing tumbling act. A cheering section helped urge the walkers over the finish line with words of encouragement. Bruce Mondschain and Larry Schaefer documented everything with their wonderful photography. Synergy Adaptive Athletics provided wheelchairs for folks to try their hand at some wheelchair basketball. Finally, a short program reminded everyone of those we have lost due to these disorders and why research and fundraising is so critical.

We want to thank the 2019 co-chairs (Nancy Dove, Debbie Bertolami, and Barbara Williams), the volunteers (Liz, John, and the Beutel family; Agnes Policarpio; Carol and John Carney; Jean Alletag; Jon Kartman; Irma and Kevin Dixler; Dan and Ann Bruch; Barbara Ray; and all who helped), and the sponsors (Viela Bio, Mark Drugs, University Associates in Dentistry, Coloplast, DuPage Acupuncture Clinic, PepsiCo, and Sheridan Road Financial) who made this event possible. We want to thank anyone who fundraised or donated. Due to all of you, the 2019 Illinois Walk-Run-N-Roll raised more than \$13,000! We also want to thank everyone who attended, brought a friend, shared the event on social media, gave a hug or words of encouragement to another attendee, picked up trash, moved a table, or said hi to someone new to our community.





## 2019 Pennsylvania Walk-Run-N-Roll

After taking a year off, Dana Deidloff and her friends and family came back stronger than ever for the 2019 Pennsylvania Walk-Run-N-Roll. The event, held on October 6th at Neshaminy High School, was a huge success, raising more than \$12,000!

The Deidloffs organized the Walk-Run-N-Roll in honor of their son, Luke, who was diagnosed with acute flaccid myelitis (AFM). More than 100 people came out on a sunny, slightly chilly day to walk, run, and roll their way around the track. A DJ was on hand to provide the tunes, and Kona Ice and Chuck's BBQ supplied the fuel that helped the participants make the lap.

Dr. Sarah Hopkins from Children's Hospital of Philadelphia (CHOP) spoke to the crowd about the importance of studying all the rare neuroimmune disorders together and touched on her experience at the SRNA Quality of Life Family Camp (which the Deidloffs also attended). Money raised through these events helps SRNA put on programs such as Camp, and we are thankful for everyone who donated or asked friends and family to donate to the 2019 Pennsylvania Walk-Run-N-Roll.

Thank you to Dana and Gary Deidloff, and all the volunteers (Jim and Melissa Cacace, Isabel and Kelly Anne Hinton, Joseph LaBella, Andrea Esposito) who made this event a huge success! And thank you to the sponsors (Viola Bio, CAI Builders, Fringe Hair Boutique, Haldeman Lexus, Summer Illusions Tanning Salon, Hamilton Police SOA, Factory Donuts, Newtown Fire Company, Villa Mannino Risotrante and Mannino's 3, and La Piazza Ristorante) who provided support! See you all in 2020!

**If you have questions about our fundraising events or are interested in organizing a Walk-Run-N-Roll, please contact Jeremy Bennett at [jbennett@wearesrna.org](mailto:jbennett@wearesrna.org).**



# New Hope Ambassador Stories

As we continue to raise awareness and learn from our community, our Hope Ambassadors share their stories of resilience, hope, and strength.



*Victoria*

**Diagnosis:** ADEM  
**Location:** New Jersey

[srna.ngo/victoria](https://srna.ngo/victoria)



*David*

**Diagnosis:** TM  
**Location:** California

[srna.ngo/david](https://srna.ngo/david)



*Louise*

**Diagnosis:** ADEM  
**Location:** United Kingdom

[srna.ngo/louise](https://srna.ngo/louise)

To read their full stories and for more information on how to become a Hope Ambassador, visit: [srna.ngo/hope-ambassadors](https://srna.ngo/hope-ambassadors). Have you been diagnosed with ADEM, AFM, MOG-Ab disease, NMOSD, ON or TM? Become a Hope Ambassador and share your journey with our community. Join our heroes and raise awareness about rare neuroimmune disorders. You can share your story by going to [srna.ngo/hope-ambassadors](https://srna.ngo/hope-ambassadors).



# Acute Flaccid Myelitis Physician Consult and Support Portal

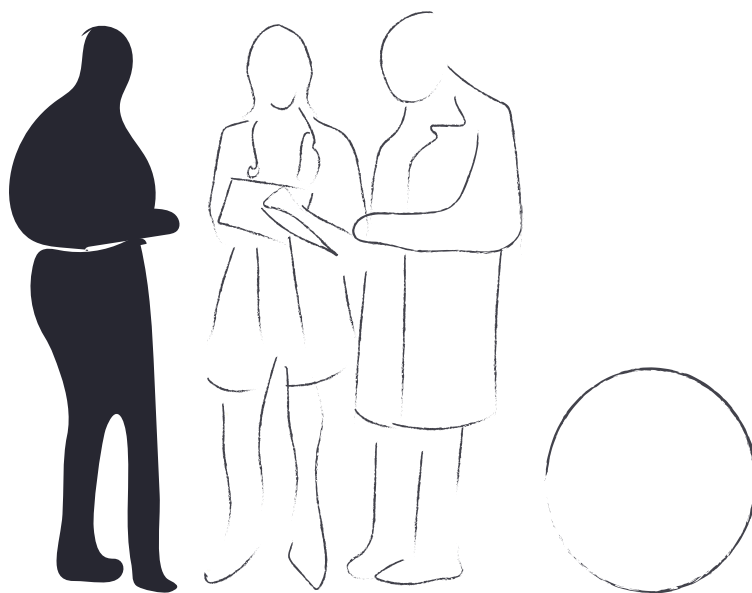
**SRNA, in collaboration with CDC, has recently launched the AFM Physician Consult and Support Portal, where clinicians can now access consultation services with AFM experts.**

The goal of the AFM Physician Support Portal is to connect medical professionals and offer 24/7 consultation. If a physician suspects a case of AFM and would like to schedule a consult with neurologists specializing in AFM and other rare neuroimmune disorders, they can complete an online form, and we will set up a peer-to-peer consult for clinical support from physicians at the University of Texas Southwestern Transverse Myelitis Center or Johns Hopkins University Transverse Myelitis Center. We know how important rapid diagnosis and treatment can be for those with AFM, and we hope this portal will connect community neurologists with experts in AFM to ensure quick diagnosis and treatment.

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**Portal:** [srna.ngo/afm-portal](https://srna.ngo/afm-portal)

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# Recap of the 2019 Rare Neuroimmune Disorders Symposium

From September 19th to September 21st, over 200 of our community members gathered in Columbus, Ohio, to participate in the 2019 Rare Neuroimmune Disorders Symposium (RNDS). Our biennial symposium is a pivotal education program for rare neuroimmune disorders. During this year's event, we celebrated the Transverse Myelitis Association's 25th anniversary and made an exciting announcement: we're changing our name! After 25 years of progress and supporting the ADEM, AFM, MOG-Ab disease, NMOSD, ON, and TM community, the TMA is now the Siegel Rare Neuroimmune Association (SRNA).

SRNA President and Founder, Sandy Siegel, and SRNA Board Member, Dr. Benjamin Greenberg, began the conference with the [name change announcement](#). They explained how SRNA is a better representation of the inclusivity and power of our organization. Dr. Greenberg remarked, *"The Board, for the last seven years, has recognized that our name was outdated. The Transverse Myelitis Association, as a title, did not represent who we were as an organization or who we were as a community... Together, as a community, we are stronger when we all live under one tent."*

Following the name change announcement, members of our community shared their stories and personal experiences with attendees. The panel provided insight into the different diagnoses, discussed the impact these disorders have on them and their families, and overall allowed event participants to connect and identify with others.

Dr. Greenberg's next presentation, *"Stronger Together,"* demonstrated how each of the rare neuroimmune disorders is connected and the benefit of studying them collectively. Sessions on the diagnosis and treatment of each of the rare neuroimmune disorders followed: transverse myelitis (TM), acute flaccid myelitis (AFM), MOG antibody-associated disease (MOG-Ab disease), neuromyelitis optica spectrum disorder (NMOSD), and acute disseminated encephalomyelitis (ADEM). These talks give an overview on each of the disorders and can be a good starting point if you are interested in learning more about them.

After a midday break, sessions continued on *"Recurrent vs. Monophasic Disorders," "Vascular Myelopathies," "Myelitis in Systemic Rheumatologic Conditions,"* and *"Updates from the TMA."* We then heard from a panel of experts on *"The Future of NMOSD Therapeutics: What Have We Learned?"* Participants included Drs. Michael Levy and Benjamin Greenberg, two members of the SRNA's Medical and Scientific Council, as well as Dr. Ankur Bhambri of Alexion Pharmaceuticals and Dr. Eliezer Katz of Viela Bio. They discussed recent developments and new medications for the treatment of NMOSD. We ended the first day of the conference with workgroup sessions on *"Finding Medical Care in Your Area," "IEPs and 504s,"* and *"ADA, Disability, and Benefits."*

• You can find recordings of all the talks on our website at: [srna.ngo/resources-2019-rnds](https://srna.ngo/resources-2019-rnds)



The second day of the conference began with Dr. Cristina Sadowsky's presentation on *"Rehabilitation and Rare Neuroimmune Disorders: Current Best Practices and Future Advances."* We then heard about research on the upcoming stem cell trial to repair the spinal cord in patients with TM and a study investigating a genetic link in individuals with TM. A panel consisting of medical researchers, a member of Centers for Disease Control and Prevention (CDC), and a member of the National Institute of Health (NIH) convened to discuss AFM and the urgent health need to address this growing concern. The panel spoke about their collaborative efforts to begin a multicenter, national research study on AFM with funding from NIH, as well as CDC's efforts to better address this growing concern.

The second half of the day began with presentations on symptom management - Spasticity, Urological Issues, Fatigue, Cognitive Issues, and Pain, Numbness, and Tingling. We learned from Nadia Barakat, PhD, about new imaging techniques for the diagnosis and understanding of rare neuroimmune disorders. Maureen A. Mealy, PhD, RN, BSN, MSCN gave us an update on *"New Trends in Pain Management,"* and Anjali Forber-Pratt, PhD presented her research, *"How is disability identity formed? Findings from a Study with Adolescents."* We then heard from a panel of medical experts on *"Pregnancy*

*and Rare Neuroimmune Diagnoses,"* followed by a talk on *"How to Manage Constipation and Prevent Accidents: Bowel Management Strategies"* by Janet Dean, MS, RN, CRRN, CRNP, CRND.

Finally, to close out the day, we heard from four of the James T. Lubin Fellows about their ongoing research, and they led an open question-and-answer session. SRNA Board Member Dr. Carlos Pardo-Villamizar closed the conference.

The 2019 RNDS was altogether an enriching and successful event. There was palpable energy surrounding the participants as a gathering this large of members of our rare disease community is powerful and unique. If you were unable to attend the event, please stay tuned for the announcement of our next symposium. We hope to see you there!



# New Information Sheet for MOG-Ab Disease

**The end of summer and start of fall is generally back-to-school time for many of our children. Back-to-school usually means re-visiting documentation and accommodations relating to their rare neuroimmune disorder.**

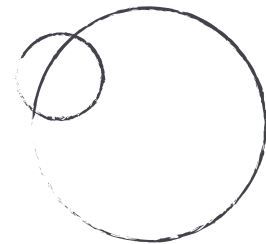
Our Resource Library includes several items that may be helpful as you prepare for meetings or ask to revisit current plans. Recently, we added an additional resource specifically for our MOG Antibody-Associated Disease (MOG-Ab disease) students and families! Thank you to our volunteers and MOG Project members for your assistance in the creation and dissemination of the MOG-Ab Disease Fact Sheet for Educators.

- Access the factsheet at:  
[srna.ngo/mog-factsheet](https://srna.ngo/mog-factsheet)

For additional educational resources, please visit our Resource Library where you may review a variety of resources, including disease-specific fact sheets, community resources, podcasts, and videos you may find helpful.

- Access our resource library at:  
[srna.ngo/resources](https://srna.ngo/resources)

Do you have suggestions and would like to contribute to additional resources related to educational needs for our community's students? Please feel free to email [rwhitney@wearesrna.org](mailto:rwhitney@wearesrna.org) with your ideas and how you may contribute towards this area of our Resource Library!



# New Treatment for NMOSD Approved

Alexion Pharmaceuticals, Inc. announced on June 27, 2019 that the U.S. Food and Drug Administration (FDA) approved SOLIRIS® (eculizumab) for the treatment of neuromyelitis optica spectrum disorder (NMOSD) in adult patients who are anti-aquaporin-4 (AQP4) antibody positive.

According to Alexion's [press release](#), "This approval is based on comprehensive results from the Phase 3 randomized, double-blind placebo controlled PREVENT trial, which were [recently published](#) in The New England Journal of Medicine. In the study, patients with NMOSD who were anti-AQP4 antibody positive were treated with SOLIRIS (n=96) or placebo (n=47). At 48 weeks, 98 percent of patients treated with SOLIRIS were relapse free compared to 63 percent of patients receiving placebo. This effect was observed through 144 weeks of treatment, with 96 percent of patients treated with SOLIRIS relapse free compared to 45 percent of patients in the placebo arm. SOLIRIS-treated patients experienced similar improvement in time to first adjudicated on-trial relapse with or without concomitant treatment. Of the patients treated solely with SOLIRIS, without receiving other immunosuppressive therapies (IST), (n=21), 100 percent were relapse free at 144 weeks compared to 20 percent in the placebo group (n=13)."

If you are diagnosed with NMOSD and are interested in receiving SOLIRIS®, OneSource™ is a complimentary, personalized patient [support program](#) offered by Alexion and tailored to the specific needs of people living with NMOSD. OneSource case managers can help you learn and understand the options that are available to you. Insurance can be complex and overwhelming. And not everyone has coverage. OneSource can assist with the navigation and identify alternative options for you. OneSource can also provide disease information, help navigate continuity of care changes, and connect you with other supportive resources.

- Access the press release at:  
[srna.ngo/aa80c](https://srna.ngo/aa80c)
- Access a summary of the N Engl J Med article at: [srna.ngo/4efa9](https://srna.ngo/4efa9)
- To learn more, contact  
OneSource at +1 (888)765-4747  
or visit [alexiononesource.com](https://alexiononesource.com)



# Clinical Studies & Trials

For detailed information about clinical studies and trials, please visit [srna.ngo/studies](https://srna.ngo/studies)

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## **01** **CAPTURE: Collaborative Assessment of Pediatric Transverse Myelitis; Understand, Reveal, Educate**

Principal Investigator: Benjamin Greenberg, MD, MHS  
Lead Study Site: University of Texas Southwestern, *Online study*

## **02** **CORE TM: Comprehensive Outcomes Registry Exploring Transverse Myelitis**

Principal Investigator: Benjamin Greenberg, MD, MHS  
Study Site: University of Texas Southwestern, *Online study*

## **03** **A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis**

Principal Investigator: Benjamin Greenberg, MD, MHS  
Study Site: University of Texas Southwestern

## **04** **Neuroimaging and Neurobehavioral Outcomes of Pediatric Neuromyelitis Optica: A Pilot Study**

Principal Investigator: Ana Arenivas, PhD  
Study Site: Johns Hopkins Medicine

## **05** **Assessment of Pediatric and Adult Encephalomyelitis Related Outcomes: Understand, Reveal, Educate or APERTURE**

Principal Investigator: Benjamin Greenberg, MD  
Study Site: University of Texas Southwestern

## **06** **Study to Investigate the Safety of the Transplantation of Human Glial Restricted Progenitor Cells Into Subjects With Transverse Myelitis**

Principal Investigator: Benjamin M. Greenberg, MD, MHS  
Study Site: University of Texas Southwestern & Children's Medical Center



## **07 Pathology of Idiopathic Transverse Myelitis**

Principal Investigator: Michael Levy, MD, PhD

Study Site: Massachusetts General Hospital and Harvard Medical School

## **08 Acute Flaccid Myelitis and Host Genetics**

Principal Investigator: Priya Duggal, PhD, MPH

Study Site: Johns Hopkins Bloomberg School of Public Health

## **09 Understanding Experiences with Vaccination Before and After a Rare Neuroimmune Disorder**

Principal Investigator: Sanford Siegel, PhD and Gabrielle deFiebre, MPH

## **010 The SRNA Registry**



Sanford J. Siegel  
1787 Sutter Parkway  
Powell, OH 43065-8806

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## Announcements

**2020 Arizona Walk-Run-N-Roll:** February 29, 2020

**2020 Quality of Life Family Camp:** July 24-28, 2020

## Contact us

**Siegel Rare Neuroimmune Association**

PO Box 826962  
Philadelphia PA 19182-6962

[info@wearesrna.org](mailto:info@wearesrna.org)

855-380-3330

[wearesrna.org](http://wearesrna.org)