



SRNA magazine

SIEGEL RARE NEUROIMMUNE ASSOCIATION

2020 / Issue 1



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) 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.

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Our education programs are supported in part through grants from



The Executive Committee of SRNA with the medical and scientific council determines the content and topics of the education programs. Sponsors are not able to influence the education programs.

A Note from the President

I hope 2020 is a good year for you and your families and that the new year brings you good health.

We will publish our 2019 annual report this spring to provide our community with an accurate and transparent view of our finances and our accomplishments. We're proud of our work in 2019 and look forward to sharing the progress we have made.

Our name change in 2019 represents an affirmation of our organization's mission and our goals. Nothing has changed about who we are and what we do. What has changed is that we have adopted a name and an identity to better reflect what we've always been: an organization that advocates for all the rare neuroimmune disorders - ADEM, AFM, MOG-Ab disease, NMOSD, ON, and TM.

This year, I am hopeful that your efforts to better educate yourself will directly and significantly impact the quality of care you receive from your physicians and therapists. SRNA offers exceptional education opportunities in the form of our website, magazines, blogs, resource library, and Ask the Expert podcast series. The SRNA team is learning from your feedback and the needs of our community and we plan to expand and improve our educational offerings. This year, we hope you will participate in our **Regional Rare Neuroimmune Disorders Symposium on Saturday, August 29th in Salt Lake City at the University of Utah**. I am hopeful that by locating this next symposium in the western states, we will facilitate participation from people who have difficulty traveling to the Midwest or East Coast. Last year, I also published a book titled *The Patient Experience with Transverse Myelitis* (available on Amazon), which I hope will be useful to some of you.

If you have one of the rare neuroimmune disorders, you do not have to go through this difficult experience alone. You can join our community and participate in support group meetings, and where a support group doesn't exist, I hope that people will step up and work with Jeremy Bennett, our Community Partnerships Manager, to start one. With our Smart Patients Online Community and our support groups across the country and around the world, you can find people to share your experiences and find the mutual care and help that makes the challenges of daily life with these disorders just a bit lighter. I am hopeful that more people will get involved to make a difference in their lives in some very positive ways.

I am more than hopeful that the families who attend our annual camp will learn a ton from our education program, which includes spending a week with medical experts on our disorders, that everyone will have a great time, and that lifelong friendships will be made between children and families from this experience.

- Read more about our name change at wearesrna.org/srna

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

- Find a Support Group in your area or start one at srna.ngo/sgn

- Read more about our 2020 Family Camp at srna.ngo/2020-camp

Since the launch of the James T. Lubin Clinician-Scientist Fellowship in 2012, we have funded the training of seven clinician-scientists to engage in critical research on these disorders, and provide exceptional clinical care to increasing numbers of people who are diagnosed, as well as to people who are living with the challenges from all of the chronic symptoms. I am hopeful that we will raise the necessary funds to grow the numbers of physicians we can train, and therefore, increase the numbers of researchers and clinical specialists.

I am hopeful that the science will continue to move forward and that we can raise the money to accelerate the pace of progress. Last year saw the approval of a new drug for NMOSD, and we are hopeful for more therapies that will be approved this year. In time, I hope there will be continued research on all the disorders to improve the diagnostic process and acute treatments and to better understand the disease process. I look forward to Dr. Michael Levy's genetics research results about transverse myelitis this year and Dr. Ben Greenberg's study enrolling the first patients in the Q cell study. In 2020, by encouraging education and awareness, promoting the science and partnering with other organizations, academic centers and federal health agencies, we will be better prepared to manage a possible spike of AFM. We can only understand these disorders if you are willing to share your experiences. Please participate in our SRNA registry (srna.ngo/registry). All of you hold the key to this knowledge.

We have a wonderful Board that remains engaged and provides guidance and support for the organization in ways that give me the greatest hope for our future. We are blessed to have such an exceptional, talented, experienced and devoted group of people involved in our organization. I hope through your participation in awareness events, meetings and educational programs, you will get to know our Board of Directors, our Officers and Executive Committee, our Executive Director, Chitra, and our staff – Jeremy, Krissy, Roberta, Rebecca and GG. Chitra keeps us all moving forward to make a positive difference in the lives of everyone in our community. Her creativity and her passion are so appreciated. It is nothing short of a miracle that we've had Chitra committed to our community for twenty years! Executive Committee Members Jim, Debbie and Linda have devoted so much of their lives, their time and energy, to creating and managing the TMA and now, SRNA. This organization wouldn't exist without them. As you will read in this SRNA Magazine, Debbie lost her husband and life-partner, Michael, just after the new year. The loss has been devastating for Debbie, and difficult for all of us who knew and loved Michael. Debbie continues to do our work every day, despite her loss. We have some amazing people involved in this organization.

I am hopeful that our staff will continue to serve our community with the same creativity, passion and devotion that they've brought to SRNA since we had the opportunity to hire a staff. We couldn't have a better group of people doing our work. We've assembled a group of people who are so well educated and trained, bring so much creativity to the work, and are so passionate

about the cause. Each of these people really cares. You can see it in how they engage with people daily on the phone, through emails and personally in support groups, education programs and awareness events. They totally get it. All of it. I am hopeful that more of you will get to know them and will appreciate these exceptional human beings in the same way that I do.

I want to thank all our donors who made a difference for us – our organization and our community – in 2019. What we do, how much we do, and how quickly we can get it done will depend on raising this money. We are so proud of all we accomplish, and nothing gets accomplished without your support. Thank you!

I hope and pray that 2020 is a great year for the Siegel Rare Neuroimmune Association. When I first started doing this advocacy work more than twenty-five years ago, I knew that we had so much that needed to be done. Pauline and I talked about it all the time. This organization and the work became our lives. What we needed to do in those early years was more about feeling than thought. We were clear about our mission; the goals were amorphous. With each passing year, and as we learn more and more, the goals have become better defined. We now have a clear definition of the work in front of us.

A very happy and healthy new year to all of you. Please take good care of yourselves and each other.

Sandy

Remembering our dear friend, Michael Capen

By Sandy Siegel

The new year began with such great sadness. We lost our dear friend, Michael Capen.

I met Debbie Capen shortly after she was diagnosed with transverse myelitis. Jim Lubin had recently started the transverse myelitis internet club (TMIC), one of the first listserv groups on the internet. Debbie was a regular participant, and I got to know her through the TMIC. We had started The Transverse Myelitis Association a few years earlier, and Debbie was interested in getting involved. Our application process in those days was simple and straightforward. How would you feel about working ridiculous hours every day of the week doing emotionally heart-wrenching work without being paid? Debbie was all in. She became the Secretary of the Association and has served on our Executive Committee and Board of Directors since that time. She's been working ridiculous hours, seven days a week, doing emotionally heart-wrenching work for free for more than two decades.

As was the case for me and Pauline, Debbie and Michael came as a package deal. When we got Debbie, we also got Michael. They were a team and were inseparable. Michael made it possible for Debbie to do this work. He was in full support of her involvement and he did his share of the work when possible. It wouldn't have been possible for Debbie to make this commitment without Michael's recognition that her contributions were important, for herself and for the community. Michael loved our community, and he was as proud as Debbie of the work that was being done.

Michael was Debbie's caregiver. He was with her through sickness and in health, and Debbie has some complicated issues. Debbie was diagnosed with TM, and then later was diagnosed with Lupus. This combination of autoimmune disorders is not unusual. We have a subset of our community who have been diagnosed with both a neuroimmune disorder and a rheumatic disorder. Debbie, unfortunately, belongs to this group. Michael has been a support for Debbie through it all.

Debbie was Michael's caregiver. Debbie has taken care of Michael in all ways. Michael focused on Debbie and on running his business. The details of living a life were left to Debbie. Debbie did life's organizing, planning and preparing. Whether making a meal, paying the bills, or packing for a trip, it was Debbie who cared for Michael.

It was a beautiful, symbiotic relationship filled with love.

If you came to camp or a symposium or an awareness event, you met Michael. He was at the registration desk with Debbie, helping to get people signed in and sharing information. If you came to camp with your family, it was Michael driving the shuttle that picked up people from the airport in Nashville to bring them to camp. He hauled the wheelchairs and suitcases into the van they rented and brought the families to camp. Michael loved meeting the families. You also saw Michael at the fishing pond, helping the children to bait their hooks and throwing their catches back into the pond. Michael was there to help Debbie and



to help all of us. Michael became a dear friend to all of us and a friend to so many in our community.

Michael was a quiet and soft-spoken person. He had an easy smile and a deep, long and sincere laugh. Michael stayed out of any kind of drama, and he avoided conflict. You never heard him make a mean or disparaging comment. I don't think I ever heard Michael say something mean or negative about anyone. He was such a positive person. Michael was a kind and gentle soul, the kindest and gentlest. Pauline loved Michael. She loved being with Michael at camp. We almost always shared a lodge with Debbie and Michael, and she spent hours in the common area talking to Michael. We became very close with the Capens, spending time with them doing the Association's work and finding time to be together socially, even though we lived on opposite sides of the country.

Debbie and Michael lived many an adventure during their more than forty years of marriage. Michael lived a good life, content with simple and uncomplicated pleasures. He loved to work. He had a carpet company and he did almost all the work on his own, from buying, to selling to installation. It was back-breaking work.

Michael loved his family and he loved his friends. Michael and Debbie were soulmates. They were there for each other in every way, they needed each other, and they were so grateful for the other.

We lost our dear friend, Michael. Debbie lost her soulmate. I've learned something about this grief journey over the past couple of years. We're going to all support Debbie the best we can. She's been a blessing in all of our lives. And we're going to keep Michael in our memories.

We love you, Debbie and Michael.

His memory should be a blessing.

Birth is a beginning
And death a destination.
And life is a journey;
From childhood to maturity
And youth to age;
From innocence to awareness
And ignorance to knowing;
From foolishness to discretion
And then, perhaps, to wisdom;
From weakness to strength
Or strength to weakness –
And often, back again;
From health to sickness
And back, we pray, to health again;
From offense to forgiveness,
From loneliness to love,
From joy to gratitude,
From pain to compassion,
From grief to understanding –
From fear to faith;
From defeat to defeat to defeat –
Until, looking backward or ahead,
We see that victory lies
Not at some high place along the way,
But in having made the journey, stage
by stage,
A sacred pilgrimage.
Birth is a beginning
And death a destination.
And life is a journey,
A sacred pilgrimage –
To life everlasting.

Rabbi Alvin Fine

Update on Genetic Study of Transverse Myelitis

By Dr. Michael Levy / Director, NMO Clinic and Research Laboratory

In 2017, we announced our discovery of a mutation in the VPS37A gene found in 3 persons with acute idiopathic transverse myelitis (ITM): 2 sisters from a Polish origin and 1 unrelated Scotch-Irish woman. Given the rarity of this mutation in the world population and in the animal kingdom in general, we proposed to screen additional ITM patients for mutations in this gene. VPS37A, which stands for Vacuolar Protein Sorting-associated protein 37A, encodes a component of the endosomal sorting complex involved in the sorting of ubiquitinated proteins into internal vesicles. The mechanism for how this gene is involved in immunopathogenesis of ITM is an active area of research in our lab. While we work to understand the scientific basis of the mutation in exon 6 of this gene and its role in the immune surveillance of the spinal cord, we expanded the screen to the rest of the VPS37A gene.

We screened the 89 original cases from samples already banked in the lab, and we also recruited an additional 45 samples remotely from sources such as Facebook and the SRNA Magazine. We found 5 additional patients with VPS37A mutations, all of which were predicted to be harmful. Notably, the new mutations are either very rare in the general population or not previously described. These findings suggest that mutations in the VPS37A gene predispose to ITM.

- Read more about Dr. Levy's study at srna.ngo/VPS37A

- Or watch this video from our 2019 Rare Neuroimmune Disorders Symposium srna.ngo/ogc



Clinical Studies & Trials

For detailed information about all clinical studies and trials, please visit srna.ngo/studies



JHTMC is now JHMMC!

In June last year, The Johns Hopkins Transverse Myelitis Center (JHTMC) celebrated 20 years of caring for people with rare neuroimmune disorders, supporting families, raising awareness, educating the community and clinician-scientists, training Fellows, and conducting basic science and clinical research.

The Center, which was the first center focused on the study of transverse myelitis (TM), was established 20 years ago by neurologists at Johns Hopkins Hospital (Drs. Douglas Kerr, David Irani and Carlos Pardo) and the support of the TM community, led by Sandy Siegel and many others in what is now the Siegel Rare Neuroimmune Association. This 20th anniversary was celebrated with a Symposium focused on the science and progress to understand TM. To reflect on achievements over the last 20 years and discuss the future, Dr. Sandy Siegel shared his personal and professional journey since the inception of the center. The day included presentations from Drs. Benjamin Greenberg, Michael Levy, Cristina Sadowsky, Olwen Murphy, Adam Kaplin, Maureen Mealy, Philippines Cabahug, Ellen Mowry, and Chitra Krishnan and GG deFiebre of SRNA.

- You can find more about the Center at srna.ngo/dsa

In the last 20 years, we have learned more about the variations in transverse myelitis, the many subtypes including the recently identified variation called acute flaccid myelitis (AFM). Diagnostic criteria have evolved, biomarkers have been identified in neuromyelitis optica spectrum disorder (NMOSD), and even genetic markers have been detected in some cases of transverse myelitis. While we reflected and learned from experts on June 22nd, 2019, it also marked a momentous announcement. Dr. Carlos Pardo announced the center's new name, Johns Hopkins Myelopathy and Myelitis Center (JHMMC), to reflect the evolution of the disorders, our understanding, and the future. "Although the diagnosis of transverse myelitis has been the way to get together around a group of spinal cord diseases that afflict many patients in our community, we may need to transition to new terms and diagnoses that provide more clarity of the problem and provide better ways to treat patients. That is why we are extending our attention to other spinal cord disorders that may look similar to myelitis but are not associated with inflammation, such as myelopathies produced by other causes which may also have a different type of treatments," Dr. Pardo commented to reflect on the increasing number of disorders that mimic myelitis but have different causes to inflammation such as strokes of the spinal cord.

Introducing the Demyelinating Disorders Clinic at the Barrow Neurological Institute at the Phoenix Children's Hospital

We interviewed Dr. Ram Narayan about the Demyelinating Disorders Clinic at the Barrow Neurological Institute. Dr. Narayan is an Assistant Professor of Neurology, Division of Neuroimmunology at the Barrow Neurological Institute in Phoenix, AZ. Dr. Narayan received his medical degree at PSG Institute of Medical Sciences and Research in Coimbatore, India, and completed a neurology residency and neuroimmunology fellowship at the University of Texas Southwestern Medical Center in Dallas, TX. Read more below to learn about this clinic!

 Read more about Dr. Narayan at srna.ngo/5b956

What is the Demyelinating Disorders Clinic and what types of services can patients receive at your clinic?

The Demyelinating Disorders Clinic at the Phoenix Children's Hospital-Barrow Neurological Institute is pleased to offer patient care in the areas of multiple sclerosis and related neuroimmune disorders. This clinic, which is the first of its kind in the Southwest, will cater to three or four neighboring states. Providers in this clinic are trained to evaluate and treat conditions like multiple sclerosis, acute disseminated encephalomyelitis (ADEM), neuromyelitis optica spectrum disorder (NMOSD), MOG antibody-associated disease (MOG-Ab disease), neurosarcoidosis, autoimmune encephalitis, transverse myelitis (TM), myelopathies, acute flaccid myelitis (AFM) and other rare neuroimmune disorders. We at the PCH will strive to provide a comprehensive multidisciplinary approach to benefit our patients.

What makes the Demyelinating Disorders Clinic unique in the world of rare neuroimmune disorders?

In addition to my fellowship training in multiple sclerosis (MS), I am also trained and certified in rare neuroimmune disorders (CRND). Some of these conditions include NMDA-R encephalitis and other forms of autoimmune encephalitis, NMOSD, MOG-Ab disease, Susac syndrome, Stiffperson's syndrome, neurosarcoidosis, IGG4 CNS disease, CNS vasculitis, TM, AFM, etc. These conditions are very different from multiple sclerosis and more often than not require complex treatment protocols and unique rehabilitation and neuropsychological needs which I am competent to provide. This makes this clinic a unique addition to the world of rare neuroimmune disorders.



What does the future of the Demyelinating Disorders Clinic look like? Are there services or additions you would like to make in the next few years?

I see the future of our clinic in three main directions. In the area of clinical care, we will soon become a comprehensive MS care center. In addition to this, we will strive towards developing a multidisciplinary MS clinic wherein our patients will benefit from consulting multiple allied specialties like physical therapy, neuropsychology, ophthalmology, dietary services, social work, etc. in a single visit. Finally, we will develop specialty clinics centered around specific disease conditions to optimize resources specific to this condition, thus making this a national referral center for a specific disease condition. With regard to research, this clinic by virtue of attracting patients with rare neuroimmune disorders, will be able to create a very conducive environment for clinical research and clinical trials. Finally, this clinic will facilitate the teaching of trainees across various specialties like medicine, nursing, rehabilitation, mental health, etc.

Are you currently doing research? If not, what type of research most interests you in the world of rare neuroimmune disorders?

My main area of research is to study cognitive aspects of MS, especially effects of MS in driving a vehicle. In addition to this, I am also studying brain volumetrics in autoimmune encephalitis. We also have plans to carry out research in the areas of MOG-Ab disease and TM.

What would be the best way for someone reading this to contact your clinic and schedule an appointment?

We are very pleased to offer our services for you/your loved one. Please contact 602-933-0970 to schedule an appointment.

Is there anything else you'd like to add?

Neuroimmune conditions, including MS, create a lot of worry in the minds of children and their parents/caregivers. There tends to be a lot of information and misinformation out there which can be overwhelming; not to undermine the complexity of these conditions. We understand how frustrating it can be to navigate through this complex health care system to obtain what you need for yourself/your loved ones. We at the PCH understand these challenges and we will try our very best to provide you with state-of-the-art clinical care and empower you with the necessary information to make this process as comfortable as possible.

AFM, are we ready for 2020?

The start of the new year and a new decade also brings a time of reflection on the past; what have we learned, what is it that we still don't know, what do we need to do to get where we need to be. Over the past decade, a sub-type/variant of what we'd known before as transverse myelitis began to occur in greater numbers. Every other year, what is now referred to as acute flaccid myelitis (AFM) spiked considerably during the late summer/early fall months, a time when enteroviruses were at a peak and children across the U.S., Canada, and the world were being diagnosed with this often devastating disorder. 2020 is one of the every-other-years that we anticipate with relative certainty an increase in EVD68 (and potentially other enteroviruses as suspect) and with it, an increase in AFM diagnoses. Why do some children develop AFM after what appears to be an otherwise common cold, but their siblings and peers who may experience the same illness recover without incident? What can we do to stop AFM from happening to our children and our families? What acute treatments work to prevent the progression of limb weakness into paralysis, or worse?

Although experts and officials have been able to identify the likely culprits of AFM in the bi-annual seasonal peaks, there are still many questions we need to answer. Getting to these answers is an incredibly difficult task. AFM remains a rare disease. We may hear of it more, know more about it, it's in the media much more than before, but it is still a rare disease. To understand what to do when someone is diagnosed with AFM, we need to understand more precisely what is happening, how it is happening, and why it is happening. Is every case being diagnosed as AFM enterovirus related? Is it a direct infection of the spinal cord? Why does only one child in a family develop AFM when four others had the same illness before the onset of the AFM symptoms? What if no enterovirus could be isolated or what if imaging shows gray and white matter damage, but the signs, the timeframe, all line-up for an AFM diagnosis? There are so many similarities between AFM and the other rare neuroimmune disorders, as well as other potential neurological and autoimmune disorders; it's difficult to fathom being the physician on the diagnostic end of these disorders. What is the difference between AFM and TM? Or ADEM? What if there are MOG antibodies present? What if we get the diagnosis incorrect? And, how do we treat these kids who come in? There is still much debate in the medical community about the acute treatments being used for AFM. There is not one that stands out as being the definitive treatment to stop the disorder in its tracks. It's critical for the treating physician to know and understand these disorders and the individual nuances of the child they are treating. It's always a hard notion to comprehend, but we don't know what the best course of treatment is in AFM.

However frustrating this may be, it's not unusual in a rare disorder. It's a monumental task to determine this ethically (we can't do a double-blind, placebo-controlled study, withholding potential life-saving treatment), and because it is rare, this makes the task even more difficult. What we do know is that timing and testing is critical; being able to be tested - an appropriate neurological exam, imaging, CSF, etc., to determine what is happening when a child comes in with sudden limb weakness or respiratory distress, after a viral illness, is critically important. We must be able to rule out that they're not experiencing the onset of AFM. We must stop the haywire immune system or virus before it can go on to cause further damage. Too many children have been sent away from the ER or pediatrician's office being told that it's "just part of the viral course", or "it's in their head" ...and that is unacceptable.

The experts and officials working in the rare neuroimmune disorders and particularly on AFM are in full preparedness mode to communicate, educate, and support the clinicians, families, caregivers, and children, who may potentially be impacted during this upcoming summer season. SRNA is working with our partners, clinicians, researchers and families, including the Acute Flaccid Myelitis Association (AFMA), the AFM Working Group, and CDC to develop further resources and communication strategies. Although most are not yet ready for public dissemination at the time of this writing, there will be updated information sheets, opportunities for clinician education, family support, and targeted communications to the medical community and public.

Our hope is that although we may be facing another spike in potential diagnoses, those who may see a child with AFM symptoms will be able to recognize, accurately diagnose, and effectively treat a child as expeditiously as possible. We know from experience in these disorders, the longer we wait, the more damage can be done. Please stay tuned to our social media, blog, and magazines as we move forward through the year. There will be opportunities for you to spread awareness with the resources and publications, or to participate in educational events. Together we can be stronger for our families who know and understand the impacts of this disorder, as well as be ready to support families, clinicians, and researchers in 2020.



AFM Physician Consult and Support Portal

In response to the 2018 bi-annual outbreak, in coordination with CDC, the AFM Working Group, SRNA, and physicians from the University of Texas Southwestern's Transverse Myelitis Center (UTSW) and Johns Hopkins Myelopathy and Myelitis Center (JHMMC), implemented the AFM Physician Consult and Support Portal.

The portal is located on our website, as well as linked to on CDC's AFM Physician Resource website. The purpose of the portal is to connect other medical professionals (e.g., ER physicians, pediatricians, neurologists, infectious disease physicians, physician's assistants, nurse practitioners, etc.) who may suspect an AFM case, to the physicians specializing in diagnosis, treatment, and research of this rare disorder. If a medical professional completes the request for a consult, they are connected with a physician from UTSW or JHMMC within 24 hours to assist. The physician consult portal is only for medical professionals to connect with another medical professional. Due to medical, state, and ethical restrictions and obligations, the professionals specializing in this disorder are only able to consult with one of their licensed peers who may be treating an individual with AFM in their own clinic.

The portal is being utilized by various professionals in the medical community and we anticipate this invaluable tool for connection to only increase in utilization as 2020 progresses, and the anticipated spike in AFM cases may rise. Making certain the medical community is aware of this resource as well as others specific to AFM is of utmost importance to SRNA.

Parents and caregivers who may suspect an AFM diagnosis or have received a diagnosis and are uncertain of what to do or where to turn next are urged to share the portal with their physicians. We also urge you to utilize the Myelitis Helpline and an SRNA team member will reach out personally to you and specifically about your questions. If it is concerning a consult with a physician, we will discuss with you the various ways in which you may be able to work with your current medical team to make that happen.

An accurate diagnosis and prompt administration of acute treatment(s) remains an essential component in recovery from an AFM diagnosis. Please continue to promote awareness within the medical community and general public about AFM, including the AFM Physician and Consult Support Portal.

Physician Consult and Portal: srna.ngo/afm-portal

Myelitis Helpline: srna.ngo/helpline



Dr. Olwen Murphy on the Completion of her Fellowship

Olwen Murphy, MB BCH MRCP received her medical degree from University College Dublin in Dublin, Ireland and completed a neurology residency at The Royal College of Physicians in Ireland. She was a James T. Lubin Fellow at Johns Hopkins Myelopathy and Myelitis Center (JHMMC) in Baltimore, MD, under the mentorship of Dr. Carlos Pardo-Villamizar. Dr. Murphy's research was on predicting outcomes after a transverse myelitis diagnosis using current imaging techniques and spinal fluid analysis. The goal of the research project was to identify patterns or biomarkers that can be used in day-to-day clinical practice to identify benefits from therapies and help make better decisions about care.

• Read more about our Fellowship at srna.ngo/fellowship

Over the past two years at the Johns Hopkins Myelitis and Myelopathy center, I have learned a huge amount about caring for patients with spinal cord disorders. I have worked with patients with transverse myelitis, spinal cord strokes, other vascular myelopathies, acute flaccid myelitis, neuromyelitis optica, anti-MOG antibody disorders and other rare causes of myelopathy. Through this work, I have learned about the diagnosis, management and rehabilitation of these disorders. My training has equipped me to move forward in establishing a career in this field. Along the way, meeting patients and their families with spinal cord problems has been a humbling and inspiring experience. Hearing how patients are making progress with rehabilitation and surmounting the challenges that spinal cord problems bring to their lives is always heartening and acts as a reminder for why we should continually strive to improve care for this group. Involvement with SRNA has allowed me to meet many patients and families in a more fun and casual setting outside of the clinic, and this is something I have really valued. My research work has led down interesting paths, and I have developed particular interest in how we can use modern MR imaging to improve diagnosis and prediction of outcome in these disorders. I recently completed my two years as a SRNA fellow funded through the James T. Lubin fellowship, and I am fortunate enough to be continuing my clinical and research work at Johns Hopkins for now. I hope to continue working in this field for many years to come, and I look forward to the challenges it will bring!



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. To read their full stories and for more information on how to become a Hope Ambassador, visit: 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.



Jeremy



Veronica



Andrea

srna.ngo/jeremy

srna.ngo/veronica

srna.ngo/andrea

2020 SRNA Family Camp

Have you applied to camp yet?! This year's SRNA Family Camp's dates are on our calendars, and we can hardly wait to see you at the Center for Courageous Kids (CCK)! July 24 - July 28, 2020, will be the long weekend for your family to get away, take a "breather" from the day-to-day, and have fun together at CCK's beautiful facility and grounds, all while connecting with other kids and families just like yours! It's an excellent opportunity to connect with friends you've met via social media but haven't yet met in person, talk to the medical professionals, clinicians, and researchers experienced in the rare neuroimmune disorders, and get to know one another and have a fantastic time together. Our Family Camp serves a variety of purposes - first and foremost, to allow your child to be a kid in spite of their diagnosis and allow them to see firsthand that they are not alone. We're confident that siblings and parents, and the children living with the diagnoses themselves, come away from camp with wonderful memories and experiences! We hope 2020 is the year we at SRNA and the supporting volunteers from our medical and scientific community

have the opportunity to meet you and your incredible family in person at CCK!

The first step: complete the pre-application on our website at srna.ngo/2020-camp! This is a "must," and then you will receive the email to complete the second part of the process, the formal CCK application. Only applications that are 100% complete, including the physician waiver form, AND the pre-application on file with SRNA, will be eligible for review for acceptance to camp. Our spaces fill up quickly, so make sure to get your application started today!

Do you have specific questions about camp? Are you uncertain if our camp is right for you or if your family may be eligible to attend? Are you a medical professional with a child/family you see whom you think may benefit from camp? Send an email or call Rebecca Whitney, Pediatrics Program Manager, and she'll be happy to talk about all things camp and answer your questions! rwhitney@wearesrna.org or +1 855 380 3330, ext 5.



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Announcements

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

2020 Regional Rare Neuroimmune Disorders Symposium: August 29, 2020

Contact us

Siegel Rare Neuroimmune Association

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