



the transverse myelitis association

newsletter

winter 2019



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

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Follow The Transverse Myelitis Association on Facebook (facebook.com/myelitis) and Instagram (instagram.com/myelitis) and tell your friends and family to do the same! It is a great way to support the TMA 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.

The Editor's Column

The Transverse Myelitis Association advocates for people who have 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). All these conditions are immune-mediated disorders of the central nervous system.

Our membership includes people with all these disorders and their family members. Our membership also includes people with vascular causes of spinal cord disorders, such as arteriovenous malformations and spinal strokes, radiation myelopathies, neoplastic disorders (tumors in the spinal cord) and Lyme disease. I'm sure there are people with other disorders of the central nervous system who have joined our Association, because they had nowhere else to go. Their symptoms are the same as the rare neuro-immune disorders, and the treatments for these symptoms are the same, as well. They likely found the TMA by searching for their symptoms. Often, the immune-mediated disorders are distinguished from the "other" disorders by referring to the former with the suffix, 'itis' and the latter, myelopathies. 'Itis' means inflammation. Myelopathy is a more general concept referring

The logo features the number '25' in a large, bold, dark blue font. Above the '5' is the text 'TMA' and to the right of the '5' is 'TH'. Below the '25' is the word 'YEAR'.

— ANNIVERSARY —

#WECARE



to conditions of the spinal cord. Our membership also includes people with multiple sclerosis, likely because their first attack was in the spinal cord, and they were given a diagnosis of transverse myelitis.

After we began the TMA, people with NMOSD and ADEM were also finding us, because their doctors were telling them that the inflammatory attack in their spinal cord was ‘transverse myelitis.’ TM was being described as a ‘symptom’ of ADEM and NMOSD; the spinal cord inflammation. This use of the term transverse myelitis has caused tremendous confusion for both physicians and patients. Many people with ADEM and NMOSD who were told they had TM believed that they had two disorders, TM and ADEM or TM and NMOSD.

The TMA has always had an open arms policy. TM is such a rare disorder. Most people who have gone through this experience have developed some serious empathy. It has been a very natural and compassionate approach for us to warmly accept anyone who could benefit from what the TMA has had to offer. In the early history of our organization, we took in everyone to offer support. We didn’t understand enough about these other disorders to think about all the benefits that could accrue from having these disorders exist under one umbrella.

Are these rare neuro-immune disorders related to each other? They could be. We really don’t understand enough today to say what the relationships could be. It is important to understand the way disorders are determined or diagnosed to appreciate what these relationships might mean. Disorders are characterized by a unique set of characteristics. No other disorder can possess the exact same characteristics. When Dr. Douglas Kerr at Johns Hopkins TM Center and the multi-institution Transverse Myelitis Working Group developed the diagnostic criteria for transverse myelitis, this is precisely what they were doing. They defined the criteria to arrive at a TM diagnosis by excluding every other possibility. They had to do it this way, because there is no biomarker for TM, and we understand so little about the disease process. TM is diagnosed through observable, clinical characteristics. Observable means using diagnostic tests like MRI and analysis of spinal fluid. TM must be differentiated from NMOSD, ADEM, MOG-ab disease, AFM and MS.

Only MOG-Ab disease and NMOSD have unique biomarkers. All the other rare neuro-immune disorders are diagnosed in the same way as TM; by differentiating the characteristics from related disorders, ruling those out, and then determining that the person possesses the unique criteria for their specific diagnosis. Developing biomarkers would be much easier and faster, and

we are advocating for this research across all the disorders. The current approach for diagnosis and treatment is not the best or likely the most effective.

All these disorders are thought to be auto-immune. It is believed that people who get an auto-immune disorder have a genetic predisposition for this auto-immunity and are exposed to certain environmental factors that trigger the inflammatory attack. We know next to nothing about either the genetics or the environmental factors that could be involved in these disorders. Having the biomarkers for NMOSD and MOG-Ab disease gets us to a more rapid diagnosis. These biomarkers are first steps in figuring out the disease process, but these are only small steps and we remain a long way from understanding the disease processes. With ADEM, AFM, ON and TM, we haven’t even made these first small steps.

We don’t understand why the attack happens. We don’t know why one person is impacted only in the spinal cord and others have attacks in the brain and/or optic nerve or optic nerves. We don’t know why a person has an attack in the thoracic region while another has one in the cervical region. We don’t know why some populations are more prone to receiving an NMOSD diagnosis. We don’t understand why AFM is happening with so much greater frequency in children. We don’t understand why some people have only one attack while others have multiple attacks. Why does TM only occur in the spinal cord?

We don’t have the slightest idea why a person who receives no acute therapy can experience a good recovery from the inflammatory attack. We don’t have the slightest idea why a person who receives high dose intravenous steroids, plasma exchange and Cytoxan can experience no recovery from the inflammatory attack.

Regardless of the rare neuro-immune disorder, physicians are going to treat them in about the same way. They will receive the same acute treatments, they will go through a similar rehabilitation regime, and then their long-term symptoms will be treated in the same way. These similarities are likely a reflection of how much we don’t understand. If we understood the disease processes, it is possible that we would develop more refined targets for acute therapy, and we might also figure out more effective strategies for rehabilitation and long-term therapies and symptom management.

Is it possible that ADEM, AFM and TM are the same disorder? Is it possible that their disease processes are closely related? Is it possible that TM is really several different disorders and

Is it possible that ADEM, AFM and TM are the same disorder? Is it possible that their disease processes are closely related? Is it possible that TM is really several different disorders and that there is some overlap between what happens to a person with TM and a person with ADEM or AFM? In my mind, that there could be relationships is not only possible, it is likely.

that there is some overlap between what happens to a person with TM and a person with ADEM or AFM? In my mind, that there could be relationships is not only possible, it is likely. In my mind, there are no bright classificatory lines around any of these diagnoses. We classify and diagnose disorders based on our current understandings. That information is severely limited. The limits are created by knowledge (or the absence of knowledge), by technology and by resources (money). What we understand about any of these disorders is based on what we can observe. Today's technology allows us to observe only so much. And limits on knowledge create barriers to where we 'look,' 'what we see,' and how we make sense of it. We move forward in our knowledge through research. Research is predicated on money. I have waited for the NIH to fund a ton of our research. That hasn't worked out all that well. There's just way too much competition for medical research dollars. I believe our best strategy for funding research is to raise the money ourselves. We're growing our discipline through the James T. Lubin Fellowship. Our program to develop clinicians and researchers has been a great success.

We need to do the same with our Pauline H. Siegel Eclipse Fund for Research on the Rare Neuro-immune Disorders! We need to control our own destiny.

As we learn about one of these disorders, it will inform our understanding of all the other disorders. As we develop more effective therapies and treatments, all these disorders will benefit. Our inclusive strategy is the most effective approach for understanding all these disorders. I have no doubt in my mind that we are going to discover even more disorders as we continue to learn. It is likely that some of those new disorders are currently being diagnosed under the term transverse myelitis today.

What occurred in our organization through serendipity has resulted in an important approach to thinking about and understanding all these disorders. I didn't recruit people with ADEM, AFM, MOG-Ab disease, NMOSD, and ON into our organization. I didn't know about any of them. Like so many occurrences in my life, I get to appear smart and insightful by

Inclusiveness at the TMA Quality of Life Family Camp

Nash (ADEM), Marcus (TM), Brienna (TM) & Leland (ADEM)



Lindsay (TM) & Ireland (NMOSD)



accident. All these people came to us. We just have a ton of compassion and took them in. That it all makes so much sense from a research and education and support perspective was an after-thought.

By looking at each of these disorders separately, we lose the synergy or the collaboration that accrues from a comparative and comprehensive strategy. That this happens doesn't have anything to do with biology or what makes sense from a research perspective. Unfortunately, some of this has to do with institutional forces that have everything to do with human behavior. This isolation process can occur in the development of medical centers and specializations. This process can occur in government institutions. It is a complicated proposition and can create artificial barriers to better understanding all these disorders, developing more effective diagnostic approaches, acute therapies and long-term disease and symptom management. This process has everything to do with power, prestige and money and nothing to do with biology. We humans can be way too complicated for our own good.

The Transverse Myelitis Association advocates for people who have 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). I am certain that the approach of including all these disorders under our umbrella will create the most comprehensive knowledge about and treatments for these disorders. I am also certain that the numbers of the disorders we advocate for will increase. I am certain that the disorders we advocate for today will change. We will find out that they are something different than what we think they are today. My thinking about these matters is often informed by Dr. Leonard McCoy, and how he characterized the stone age of medicine (today).



Sarah (AFM), Sydney (TM) & Hannah (ADEM)



Austin (AFM)



Given our expansive and comprehensive thinking about the rare neuro-immune disorders, the name of our organization has been and remains a significant problem. In 1994 we were all about transverse myelitis. Nothing else. Today, 25 years later, we are so much more than The Transverse Myelitis Association. I've known this was a problem for a long time. I've felt horribly about it. I've also felt horribly about war, famine and poverty, and have felt equally capable of attacking all these problems in the same manner. Honestly, the thought of changing our name just seemed way too overwhelming while working full time, raising two teenage sons, serving as Pauline's primary caregiver, taking care of a home, and managing the TMA as a part-time volunteer.

2019 marks the TMA's 25th year Anniversary. Birthdays and anniversaries that end in zeroes and fives are generally given more significance in our culture and many cultures because they are landmarks and evoke more self-reflection. I think the best way to do this is recognize that what we have done in the

past 25 years has made such a big difference for the people in our community.

It is imperative that our name be inclusive and represent the comprehensive approach we take to advocacy, education, support and research. The name is going to change. We will need your help in making this change, because this is your organization. And what better time to do this than our 25th birthday. We are seeking your understanding and assistance as we begin this new journey for your organization.

I hope that this is a wonderful new year for you and your families, filled with good health, happiness and peace.

Please take good care of yourselves and each other.

Sandy

WHO CARES if I can't always get what I want?

if obstacles keep getting in my way?

if I keep pushing but can't get where I want to go?

if everything takes me five, ten, twenty times as much effort?

if mornings are just too rough?

if I can't get out of bed?

Or run?

Or walk?

Or move my arms?

Or breathe on my own?

WHO CARES if there is still nothing that can fix it?

Well... **WE DO.**

WE CARE.

Do you?



Rare neuro-immune disorders can affect anyone, but **everyone** can play a part in fighting back. Only research has the power to change the future.

For our 25th Anniversary, we just ask you to do one thing:

CARE

who-cares.us/#icare

Ten +1 Ideas to Kick Off the TMA's 25th Anniversary

This year marks the 25th Anniversary of the TMA. 25 years of hard work, perseverance, and continuous improvement to design better programs and services for our community. With this in mind, we believe that everyone has a role in improving the quality of life of people with rare neuro-immune disorders, including you. Join us in raising money and awareness and make our 25th Anniversary a year to remember for years and years to come. Help us raise the money that will accelerate and intensify research on all of these rare disorders and also grow our discipline so that more research is possible, and more people have access to good clinical care. We can't do it without you.

Below are some ideas to help get you started. As always, if you have other great ideas, we'd love to hear them. Please contact Jeremy Bennett at jbennett@myelitis.org for more information and tell him how you plan to get involved. He'll even send you cool 25-year TMA materials to use.

Organize a 25-year Anniversary Walk-Run-N-Roll in your area

In 2018, there were five Walk-Run-N-Roll events organized by our members. This year we'd like to double that number. These events are a great way to raise awareness and funds, and to meet others. Last year, an average of 100 people registered for a Walk-Run-N-Roll. This year, we have our special 25-year branding ready to be showcased at your very own Walk-Run-N-Roll!

Host a restaurant fundraiser

As Barbara mentions in her article on page 14, hosting a restaurant fundraiser is a simpler way to get involved...and you don't have to know someone who owns a restaurant. Groupraise (www.groupraise.com) is a great site that allows you to search by zip code for restaurants in your area that will give a percentage of sales to the TMA.

Ask a local business to donate a percentage of sales to the TMA

Speaking of local businesses...you don't have to use a restaurant. Ask your yoga teacher, dry cleaner, or favorite retail shop to donate a portion of their sales on a certain day. Our friends at The Candle Lab in Pittsburgh, PA donated nearly \$1000 last May as part of our Candles for a Cause event.



Organize a bake sale and a lemonade stand

From things that smell good to things that taste good: set up a bake sale at your work, church, or school. People are going to need a drink to wash down those delicious cookies. Do you have kids? Let them get involved and do an old-fashioned lemonade stand.

Set up a Casual Friday at work

No one likes wearing work clothes. Be the best friend of all your co-workers and plan a Casual Friday fundraiser. Each person who donates gets to dress down. TGIF indeed!

Create an online fundraiser

Two things that everyone has: Facebook and a birthday. Combine them and ask your friends to donate to the TMA in lieu of buying you a gift. These fundraisers are easy to do and make a big difference! Not a fan of Facebook? Or birthdays? Not to worry! You can always create a fundraiser through our website (myelitis.org/fundraise) and share it with family and friends. Just as easy!

Get a pair

Donate \$25 or more and we will give you a pair of the warmest, coolest, and most caring socks in town. Get your special pair of #CARESOCKS by going to: caresocks.org/c5. This will not only make your feet look good, but also spread awareness about rare neuro-immune disorders!

Become a monthly supporter

Recognize this special 25-year anniversary of the TMA by making a commitment to make a monthly donation of \$25 each month during the year. If you can afford \$250 a month, that would get us even closer to helping us achieve our/your important goals. You will, of course, get a pair of #CARESOCKS as a thank you. Become a monthly supporter at myelitis.org/donate/give-monthly.

Share your story

Want to raise awareness or share positivity? Write your local newspaper's health reporter and tell them your story. Or, become a TMA Hope Ambassador and help share a message of encouragement to our community. Submit your story here: myelitis.org/about/hope-ambassadors.

Write or call your politicians

Take it a step further and write a local politician. Do you want to see better funding for healthcare? Is there a prescription drug bill that you are hoping will pass? Write or call your elected officials and tell them your story. And make sure to let us know about it!

Start an Awareness Day

Go a step further and get a day in honor of your diagnosis. Our Georgia Support Group Leader, Kim Harrison, is participating in her fourth Rare Disease Day in Atlanta. She's also worked with the legislature to get February 15 to be Georgia TM Awareness Day.

Eating Out for a Good Cause

By Barbara Sattler

Barbara Sattler is on the Board of The Transverse Myelitis Association. While a city court magistrate in Tucson, Arizona, Barbara contracted transverse myelitis. She took four months to recover before returning to work and was later appointed to the superior court bench. Barbara retired in 2008. Since retirement, she has written three novels and has committed all her publications' proceeds to the TMA. Barbara's books are available for purchase on amazon.com. Barbara also has a blog on barbarasattler.com.

Many of us think of fundraising as fancy dinners, silent auctions, golf tournaments and, of course, the walk-run-n-rolls. Those events are fabulous and generate lots of money. They also take lots of planning and time. For many of us, the thought of putting on an event like that is daunting. For some of us, getting out of bed in the morning is daunting.

Recently, I had a much simpler idea that can be done by one person, although Julie Barry, a TMA member, and I did it together. My son Ben (and his partner) recently opened The Drunken Chicken, a restaurant whose specialty is chicken and waffles, and craft beers, but also serves a variety of chicken sandwiches, burgers, ice cream and waffles, mac and cheese, and funky appetizers.

Ben was willing to let us do a fundraiser there. Between 4 and 8 pm one evening, 25% of all sales were donated to the TMA. We also set up a table and gave anyone who came in a TMA bracelet and a brochure about the TMA. As one of my friends said, "Great idea, eat for charity."

Julie and I publicized the fundraiser on Facebook and with individual invites to friends, book club members, and family. Facebook gave us the option of a donate button which allows people to donate immediately on the Facebook page (at no cost to the TMA or the Facebook user). Folks who couldn't show up that evening sent donations through Facebook, by mail or in person

This is an easy way to raise money. Little preparation. Lots of fun. Our family and friends attended, plus people who just came to eat and wound up learning about the TMA. Some gave more.

I was lucky to have a son in the restaurant business. You can do an event like this with other businesses besides restaurants, such as a hair salon or sports business. If the items are higher end, you might consider a smaller percentage given to TMA. All you need is one person in business who wants to help.

As a reminder, if you buy from Amazon, sign up for Amazon Smile. It costs you nothing, but a small percentage of whatever you spend goes to the organization you specify which is, of course, the TMA.

New Hope Ambassador Stories!

Our Hope Ambassadors shared their stories of resilience, hope, and strength. As we continue to raise awareness and learn from our community, we are honored to share the stories of three new Hope Ambassadors: Itika, Ami, and Elliana.



Itika S.

Diagnosis: TM
Location: India

tma.org/itika



Ami T.

Diagnosis: TM
Location: United Kingdom

tma.org/ami



Elliana M.

Diagnosis: TM
Location: Oregon

tma.org/elliana

To read their full stories and for more information on how to become a Hope Ambassador, visit: tma.org/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 neuro-immune disorders. You can share your story by going to tma.org/hope-ambassadors.

Letter to the TMA Community from Dr. Allen DeSena, the first TMA James T. Lubin Fellowship Recipient

Dr. Allen DeSena attended medical school at Loyola-Stritch School of Medicine in Maywood, IL, located in the greater Chicago area. From there, he went on to complete a residency in general pediatrics in New Orleans, LA at the Tulane-Ochsner pediatric program, and he earned his board certification in general pediatrics in 2009. Following his general pediatrics training, he moved to Dallas, TX, where he completed a residency in pediatric neurology at UT-Southwestern Medical Center in conjunction with Children's Medical Center-Dallas and Parkland Memorial Hospital. During that time, his interest in transverse myelitis and other neuro-immunologic disorders blossomed, and he pursued further training in those areas. In 2012, he was the recipient of the first James T. Lubin Fellowship Award from the TMA to pursue a clinical and research career in transverse myelitis and other related disorders mentored by Dr. Benjamin Greenberg, Director of the TM and NMO Centers at UTSW in Dallas. He was the first pediatric neurology fellow to study the rare spectrum of neuro-immunological disorders, with a particular focus on transverse myelitis. Prior to his current position, he was an Assistant Professor in the University of Cincinnati Department of Neurology and Rehabilitation Medicine in Ohio. Currently, Dr. DeSena practices in Charlotte, NC at Atrium Health: atriumhealth.org/provider-profile/allen-desena-1770764060.

Greetings to all!

I first would like to say that I am wishing you all the best, for those in the TMA community as patients, family members, and our supporters. I hope this new year finds you well and ushers in the potential for positive change and better answers for those struggling with a diagnosis of one of the rare neuro-immune disorders.

My family and I have moved to Charlotte, NC. My wife and I are grateful for the opportunities this move has created. I will be able to more solely focus on adult and pediatric patients with rare neuro-immune disorders. I am in discussions with the head of Child Neurology at Levine Children's/Atrium Health about ensuring we are a positive resource and destination for all of the diagnoses for which the TMA advocates.

A special thanks to Dr. Michael Sweeney (a former James T. Lubin Fellow) for helping find a medical home for many of my former patients in the greater Cincinnati area. Not surprisingly, he was a rock star during this time of need.



I will continue to work hard on advocating for and focusing on the rare neuro-immune disorders. Answers are so desperately needed. I am hopeful that the Centers for Disease Control and Prevention (CDC) will take a broader look at myelitis and expand their focus outwards from AFM. I would encourage all families, patients, and supporters to contact their congressperson(s) at the federal level to stress that ALL cases of myelitis need to be explored, both prospectively and retrospectively, by the CDC. Obviously, Dr. Benjamin Greenberg from the University of Texas Southwestern Medical Center has been doing great on this front, but more person-power can only help us!!

I hope to be able to give a more impactful and substantive update later this year. Best regards to the TMA community and to all its supporters.

Sincerely,
Allen DeSena

Three New Drugs Have Shown Promising Results in the Treatment of Neuromyelitis Optica Spectrum Disorder (NMOSD)

Currently, there are no FDA-approved treatments for NMOSD, so all of the current treatments are used off-label. However, the drugs used in these studies were all proven to be effective and new therapeutic options may be available to people with the disorder.

Each drug that was studied works differently. Inebilizumab targets specific cells that play a part in causing relapses. Satralizumab targets IL-6, a protein that can cause body-wide inflammation. Eculizumab appears to reduce a substance at the neuromuscular junction (the place where neurons tell muscles to contract).

The main objective of the studies was to prevent a relapse, or the return of NMOSD symptoms. It's exciting to report that each trial achieved that objective.

N-Momentum is the name of the study that used inebilizumab, a drug from Viela Bio. The researchers found that patients treated with the drug had a **77% reduction in the risk of developing an NMOSD attack and a reduction in worsening of disability** compared with those given placebo.

And more hopeful news—a drug called satralizumab from Chugai also reached the objective in its study, which was to significantly reduce the risk of relapse.

Eculizumab, a drug by Alexion that is also used to treat a condition called atypical hemolytic-uremic syndrome (aHUS), was tested in people with NMOSD. The Phase 3 'PREVENT' study of eculizumab in patients with NMOSD showed a **94.2% reduction in the risk of relapse** compared to placebo.

Eculizumab also helped prevent relapse over time. **At 48 weeks, 97.9% of patients** receiving eculizumab **were free of relapses compared to 63.2% of patients receiving placebo.**

For more information on treatments for NMOSD: myelitis.org/resources/new-drugs-horizon-nmosd

The TMA Registry Update

The TMA Registry was developed over two years ago as a research initiative to help us better understand people's experiences with rare neuro-immune disorders. The Registry collects information from individuals diagnosed with one of these disorders about their experiences and treatment. Through the data collected from this survey, we hope to learn more about what pre-onset factors are associated with an inflammatory attack, the symptoms experienced at onset, the acute treatments that are administered, the rehabilitation therapy received, ongoing symptoms that are experienced, and the overall affect that these disorders have on quality of life. The TMA Registry's other purpose is to create a database of possible participants for future research.

To date, the TMA Registry has had 208 participants complete the survey. Of the respondents, approximately 82% are diagnosed with transverse myelitis, 7% are diagnosed with neuromyelitis optica spectrum disorder, 5% are diagnosed with acute disseminated encephalomyelitis, 2% are diagnosed with acute flaccid myelitis, 1% are diagnosed with MOG antibody-associated disease, and 7% are diagnosed with another disease or have yet to receive a diagnosis. Any individual diagnosed with a rare neuro-immune disorder, or the parent or caregiver of a child under 18-years-old who is diagnosed with one of these disorders, may participate.

We rely on the voluntary participation of our community members in research projects such as the TMA Registry to help us better understand these disorders. Research is the best way to improve the quality of life for individuals with rare neuro-immune disorders, and we are hopeful for a brighter future with the work that is being done in this field. If you would like to participate in the TMA Registry, please visit tma.org/tma-registry.

Facts About Rare Neuro-Immune Disorders: The 5 W's

By Dr. Cynthia Wang

Neuro-immune disorders, such as 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) are conditions in which a person's immune system mistakenly attacks parts of the central nervous system (CNS) – brain, spinal cord, optic nerve.

Who gets these illnesses?

ADEM tends to affect young children, typically ages 4-8, without a significant bias for specific gender or ethnic background.

AFM tends to affect children as well, and increases in cases have occurred every other year since 2012.

We are still learning about who is more likely to get **MOG-Ab disease**. Some studies have shown that those with MOG Antibody-Associated Disease are on average younger and are likely to be male compared to those with aquaporin-4 (AQP-4) positive NMOSD. Those with MOG-Ab disease may be more likely to have bilateral involvement of the optic nerves.

NMOSD associated with AQP-4 antibodies tends to disproportionately affect non-Caucasian women in their 30-40s.

ON is more common in women and develops in most patients between the ages of 20 and 45. Additionally, ON typically occurs more frequently in Caucasians than African Americans.

TM can affect individuals of all ages, ethnicities, and either gender.

Where in the nervous system do these disorders affect?

Inflammation in optic nerves = optic neuritis (ON)

Inflammation of spinal cord, primarily the white matter of the spinal cord = transverse myelitis (TM)

Inflammation of spinal cord, primarily the grey matter of the spinal cord = acute flaccid myelitis (AFM)

Inflammation of brain = encephalitis

Inflammation of brain and spinal cord (and sometimes optic nerve) = encephalomyelitis (acute disseminated encephalomyelitis (ADEM) is a subtype that may or may not include spinal cord involvement)

Inflammation of brain, optic nerves, and/or spinal cord = neuromyelitis optica spectrum disorder (NMOSD) or MOG antibody-associated disease (MOG-Ab disease)

What does monophasic or relapsing mean?

Some of these disorders are monophasic, meaning a one-time confused reaction of the immune system, without any further episodes of inflammation (TM, AFM, ADEM, ON).

Other disorders are known as relapsing, in which a persistently confused immune system can continue to cause inflammatory episodes (NMOSD and MOG-Ab disease, although ADEM, TM, and ON can be initial presentations of these relapsing diseases)

For the disorders that can be relapsing, people are given long-term therapies to diminish the chance of future episodes or to lessen their impact should they occur.

Testing for AQP4 and MOG antibodies can help predict if someone will have a monophasic or relapsing course.

If antibody testing is negative, the longer one goes without another attack, the more likely it is that the condition is monophasic.

Which of these conditions tend to be relapsing or recurring?

Multiple sclerosis and neuromyelitis optica spectrum disorder associated with aquaporin-4 (AQP-4) antibodies are the two most well recognized forms of relapsing CNS auto-immune disorders.

60-80% of individuals with optic neuritis and longitudinally extensive transverse myelitis (involvement of greater or equal to the length of 3 vertebrae) have antibodies to aquaporin-4 (AQP-4), a water channel in astrocytes, a type of support cell in the central nervous system.

A proportion of individuals who test negative for AQP-4 and some of those diagnosed with recurrent ON or ADEM are now known to have antibodies against another target, called myelin oligodendrocyte glycoprotein (MOG). MOG is a protein on myelin and oligodendrocytes, the myelin-producing cells of the central nervous system and are thought to have MOG-Ab disease. Individuals who continue to test positive for MOG antibodies 6-12 months after their initial attack are at risk for recurrent disease and should discuss with their provider if chronic immunosuppression is warranted.

Why do people get these disorders?

This is a central question in neuroimmunology and currently we still don't know for sure. It is hypothesized that these disorders result from a specific set of circumstances, namely 1) a person whose immune system may be primed to overreact or get confused, or a genetic predisposition to auto-immunity and environmental triggers, and 2) a life event, perhaps a bodily stressor, such as an infection, to trigger the attack. We do not yet know the genetics or environmental factors that lead to these conditions.

Q&A on Relapsing vs Monophasic Rare Neuro-immune Disorders with Dr. Cynthia Wang

Are diseases such as transverse myelitis (TM), acute flaccid myelitis (AFM), optic neuritis (ON), acute disseminated encephalomyelitis (ADEM), MOG antibody-associated disease (MOG-Ab disease), or neuromyelitis optica spectrum disorder (NMOSD) one-time or relapsing diseases?

It depends. TM, ON, and syndromes resembling ADEM can occur in the setting of relapsing conditions, such as multiple sclerosis, neuromyelitis optica associated with aquaporin-4 antibodies (AQP-4), and some systemic/rheumatologic diseases. Once an individual has undergone sufficient workup for these conditions and they have been ruled out, the likelihood he or she has idiopathic transverse myelitis or monophasic ADEM increases, which are considered one-time disorders. In the past year, clinicians have also been able to test for a new antibody called MOG (myelin oligodendrocyte glycoprotein). Like AQP-4, MOG antibodies can be assessed with good accuracy through a blood sample. Although the MOG story is still unfolding, many physicians following patients who continue to test positive for MOG antibodies 6-12 months after the initial episode have reported relapsing disease in this population and are thought to have MOG antibody-associated disease.

I had transverse myelitis (TM), optic neuritis (ON), or acute disseminated encephalomyelitis (ADEM) in the past and was told I don't have multiple sclerosis or neuromyelitis optica spectrum disorder (NMOSD). I am now experiencing new or worsening neurological symptoms? What should I do?

It is very important for you and your provider to determine if the worsening symptoms are related to new inflammation (i.e., a relapse), or from some temporary disturbance in your body's normal state unmasking symptoms from a prior injury, without new inflammation (pseudo-relapse).

For symptoms that last over 24 hours and do not improve with rest, hydration, being in a comfortable temperature, and/or recovery from an acute illness (e.g., respiratory or urinary tract infection), contact your neurology provider. He or she may order blood or urine tests to make sure you are not experiencing any acute infections or metabolic disturbances. If ruled out, additional tests may include an MRI of suspected area of new inflammation (i.e., brain, spine, and/or optic nerves).

Evidence of new inflammation on MRI and/or symptoms related to a part of the nervous system that was not affected in the past suggests a new acute inflammatory episode. This should be treated with immunotherapy such as corticosteroids to stop ongoing inflammation, and trigger a discussion with your clinician about whether ongoing immunotherapy to prevent another attack is needed.

If I am concerned I have a relapsing disorder, what should I do?

Discuss this concern with your neurology provider, and ask if you would be an appropriate candidate to test for AQP4 and MOG antibodies (available through Mayo Medical Laboratories as "CDS1" order).

My doctors say they can still see TM or an area of damage on my MRI. Does this mean I have a relapsing disorder?

During an inflammatory attack in the spinal cord, as occurs in TM, there may be evidence of inflammation on MRI (areas of contrast enhancement indicating compromise of the blood-brain-barrier) or an increase in inflammatory cells in cerebrospinal fluid). After this inflammation subsides, there may be evidence of where this attack occurred, or an area showing previous damage (T2/FLAIR abnormalities), but not ongoing inflammation (e.g., continued contrast enhancement). Gliosis, essentially a scar in the brain, can be seen for months or years and does not indicate ongoing inflammation or relapsing disease. An MRI that shows new inflammation suggests a new acute inflammatory episode.



Dr. Wang received her medical degree from University of Texas Southwestern Medical Center in Dallas, Texas and completed a pediatrics and pediatric neurology residency at Mott Children's Hospital, University of Michigan Health System in Ann Arbor, Michigan. Dr. Cynthia Wang completed her James T. Lubin Fellowship under the mentorship of Dr. Benjamin Greenberg at The University of Texas Southwestern and Children's Health. Her research study was a prospective, longitudinal study on acute disseminated encephalomyelitis (ADEM) to identify the clinical characteristics, treatment methods, and follow-up interventions that are associated with better and worse patient-centered outcomes.

My doctor told me I am AQP4 positive, now what?

An episode consistent with neuromyelitis optica spectrum disorder and a single positive test for AQP-4 in blood or spinal fluid are typically adequate to establish a diagnosis of NMOSD. These individuals should be placed on immunosuppressive therapy, which we currently advise be continued indefinitely. This is because NMOSD attacks can be severe, cause lasting visual or motor impairment, and are very likely to recur unless treated.

My doctor told me I am MOG positive, now what?

This depends on when MOG antibodies were tested in relation to your demyelinating event. If MOG antibodies were detected at the time of the attack or in the first 6 months following attack, we recommend retesting for MOG antibodies 6-12 months after your event. If you become MOG negative, you are unlikely to have future relapses.

If MOG antibodies are positive again, you are considered to have MOG antibody-associated disease, and may be at risk for future demyelinating episodes. You should speak to your neurologist about whether you should be placed on a therapy to prevent the likelihood of a relapse.

For individuals who undergo MOG testing for the first time 12 months or greater after their demyelinating event, one positive MOG test would be sufficient to diagnosis persistent MOG antibodies and then you should have a discussion with your physician as above about chronic immunotherapy.

I already have any existing diagnosis of multiple sclerosis or neuromyelitis optica spectrum disorder. Should I be tested for MOG?

It depends on your clinical history and if you have tested positive for AQP-4. MOG testing is reasonable in people who've been told their presentation is atypical for multiple sclerosis and neuromyelitis optica spectrum disorder and previously have been negative on AQP-4 testing. AQP-4 positive patients with symptoms consistent with NMOSD do not need MOG testing, as being double positive (MOG and AQP-4 positive) is exceedingly rare. In addition, this information ultimately would not change management as recurrent MOG and AQP-4 associated NMOSD are currently managed very similarly.

People with presumptive multiple sclerosis who do not respond as well as expected to MS drugs should have a discussion with their doctor about MOG testing as MOG syndromes can be misdiagnosed as MS. A positive MOG test may change medical management as some MS therapies might be ineffective or perhaps even exacerbate MOG antibody-associated disease.

People with MRI and spinal fluid studies consistent with multiple sclerosis should not be routinely screened for MOG antibodies, but decided on a case-by-case basis after discussion with a neurologist.

Glossary

Central Nervous System: Includes the brain, spinal cord, and optic nerve.

Monophasic rare neuro-immune disorder: A disorder that causes only one episode of inflammation in the central nervous system.

Recurrent or relapsing rare neuro-immune disorder: A disorder that causes more than one episode of inflammation in the central nervous system.

Relapse: New inflammation in the central nervous system.

Pseudo-relapse: Temporary disturbance in the body's normal state unmasking or worsening symptoms from a prior injury, without new inflammation in the central nervous system.

Attack: An event of inflammation in the central nervous system.

Onset: The first symptoms of a rare neuro-immune disorder. Typically, the first attack.

Inflammation: Part of the body's immune system meant to eliminate noxious agents. In rare neuro-immune disorders, the immune system mistakenly attacks the brain, spinal cord, or optic nerve, causing inflammation in these areas.

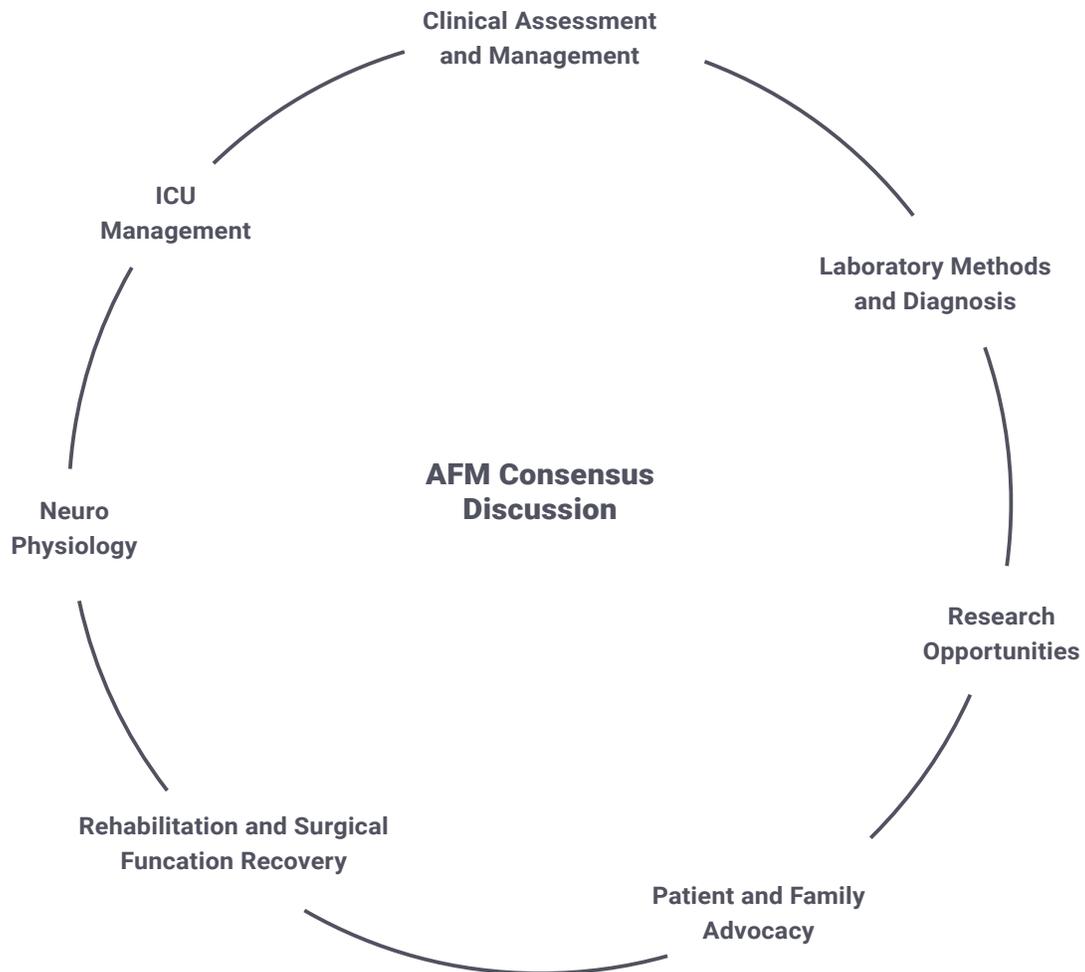
| Disorder | Areas of CNS Involvement | Specific Diagnostic Tests | Relapsing or Monophasic | Ongoing Immunosuppression indicated? |
|----------------|--|--|--|--------------------------------------|
| ADEM | Brain Spinal Cord Optic Nerve | None if monophasic | If MOG negative 6-12 months after onset, typically monophasic | No |
| | | MOG Antibody | If MOG positive 6-12 months after onset, might be recurrent (MOG-Ab disease) | Yes |
| AFM | Spinal Cord (primarily grey matter) | Enterovirus PCR in CSF (though virus is very difficult to isolate), positive enterovirus/ rhinovirus on respiratory specimen is supportive | Monophasic | No |
| Mog-Ab Disease | Brain Spinal Cord Optic Nerve | MOG Antibody | Uncertain, persistence of MOG antibodies are associated with relapsing disease | Yes, if relapses occur |
| MS | Brain Spinal Cord Optic Nerve | None, though CSF oligoclonal bands are supportive | Relapsing | Yes |
| NMOSD | Brain Spinal Cord (typically lesions more than 3 vertebral segments in length) Optic Nerve | Aquaporin-4 antibody | Relapsing | Yes |
| ON | Optic Nerve | None | Depends if ON is a part of MS, NMOSD, or MOG-Ab disease | Typically yes if relapsing |
| TM | Spinal Cord (primarily white matter) | None | Monophasic | No |
| | | | In very rare cases can be recurrent | Case-by-case |

AFM Spotlight

AFM Working Group Announcement

A couple of months ago, several clinicians and health care providers established the AFM Working Group. The Group consists of medical professionals and researchers from approximately 25 institutions and is under the leadership of Dr. Carlos Pardo from the Johns Hopkins Transverse Myelitis Center. The TMA is a part of this working group, and is committed to advancing the knowledge, research and education in partnership with the group. The broad goals of the AFM Working Group are:

- **To share the experience of each medical center, current projects, and clinical approaches to AFM**
- **To generate strategies for improving diagnosis and management**
- **To generate consensus and guidelines for the management of the clinical problems of children affected by AFM**
- **To discuss ideas and coordinate research efforts of pediatric neurologists, infectious disease specialists, genetic epidemiologists, and others for confronting the outbreak of AFM with a collaborative and comprehensive effort**



The diagram above shows the larger organization of the various goals of the group and also reflects the sub-groups working together to achieve consensus.

The subgroups of the AFM committee include the Intensive Care Unit (ICU) team, the Neuro-physiology team, the Rehabilitation team, the Clinical Assessment and Management team, the Laboratory Methods and Diagnosis team, the Research Opportunities team, and the TMA AFM Parents subgroup. Each subgroup has been meeting on their own to discuss current methods of practice and to reach a consensus across centers for the best approach. The ICU team, for instance, has created a list of criteria to determine when children with AFM should be intubated if needed. The Rehabilitation group is creating

guidelines for rehabilitation when the child is still in the ICU, which is critical for children with AFM's long-term success.

The AFM working group met weekly throughout the last two months of 2018 to discuss these practices and collaborate on a consensus. The group hopes to publish a consensus article in a scientific journal so that physicians and health care professionals across the country can learn how to best handle cases of AFM. The group is also in the process of establishing criteria for collecting clinical data and biological samples so that a multicenter research study can be conducted. It is important for the data to be collected uniformly across all participating medical centers so that an analysis can be performed.

Three Articles About AFM Published in JAMA Pediatrics

On November 30th, *The Journal of the American Medical Association (JAMA) Pediatrics* published three articles about acute flaccid myelitis (AFM). One article, “A Parental Perspective on Strengthening Knowledge After Acute Flaccid Myelitis,” was written by three mothers of children with AFM, Dr. Riley Bove, Heather Werdal, and Erin Olivera.¹ They discuss their experiences caring for their children, as well as supporting other parents faced with this diagnosis through a Facebook group for parents of children with AFM. They explained that when they brought their children to a physician for evaluation of weakness, the physicians often did not perform a neurological examination that would have revealed the limb weakness. Often, they dismissed this weakness as insignificant, which led to delays in diagnostic tests and treatment “...The delay in evaluation represented the first of a series of schisms between us and the health care system that eroded our trust that our children’s cases were taken seriously, reported to the CDC adequately, and followed up with care.” They also note their ongoing role as caregivers for their children and the need to deal with complications, such as scoliosis and pain. They urge medical providers to advocate for greater insurance allowances for rehabilitation, and a greater willingness to work with their children’s schools and therapists.

The authors write, “*We share this perspective with the hope that early awareness, intervention, and advocacy will prevent AFM from becoming more common and will help our affected children achieve a future where they are not defined by their AFM.*”

Earlier this fall, several clinicians and health care providers established the AFM Working Group. The Group consists of medical professionals and researchers from approximately 25 institutions and is under the leadership of Dr. Carlos Pardo from the Johns Hopkins Transverse Myelitis Center. The TMA is a member of this working group, and is committed to advancing the knowledge, research and education regarding AFM. Dr. Sarah Hopkins, Dr. Matthew J. Elrick, and Dr. Kevin Messacar, in partnership with the working group, wrote an article about the diagnosis, treatment, and future directions for AFM.² They discuss key diagnostic features found through lumbar puncture and magnetic resonance imaging (MRI) of the spinal cord. They discuss the identification of infections associated with AFM, such as enterovirus D68 and enterovirus A71. They argue that when AFM is suspected, patients should be hospitalized with a concern for the progression of weakness or loss of the ability to breathe. They discuss potential treatment options and note

that intravenous immunoglobulin (IVIG) has been widely used, but that there are mixed opinions about the use of steroids or plasma exchange. They argue that “this is an area in urgent need of further research” and note the importance of early and continued rehabilitation.

Following outbreaks of AFM in 2012 and 2014, the U.S. Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists created a standardized case definition for this illness which could be used for epidemiological surveillance.³ This definition has been used by clinicians to diagnose and treat children presenting with this illness and by scientists to define research cohorts. While the CDC’s definition has been used to identify cases for the purpose of surveillance, it may need to be refined so as not to encompass other rare neuro-immune disorders, such as transverse myelitis, Guillain-Barre syndrome, spinal cord stroke, acute disseminated encephalomyelitis, MOG antibody-associated disease, and other myelopathies.

Researchers, many of whom are part of the AFM working group, conducted a retrospective analysis which included the cases of 45 children younger than 18 who were diagnosed with AFM in the United States and Canada between 2012 and 2016. The records came from patients who self-referred or were referred by their physicians for a study of genetic susceptibility to AFM, and patients presenting with suspected AFM to the Johns Hopkins Transverse Myelitis Center between 2014 and 2017. The two goals of the study were to determine whether the CDC case definition of AFM includes patients with different diagnoses and to identify clinical characteristics that differentiate AFM from other diagnoses. Neurologists reviewed the medical records and MRIs (when available) of all patients and categorized them as either patients with “AFM with possible alternative diagnosis” (AFM-ad) or patients who met only the CDC case definition for AFM and no other alternative diagnosis, which they called “restrictively defined AFM”, or rAFM. The researchers then compared each clinical variable in the patients’ medical records to generate a description of rAFM; those characteristics that were present in all patients in the rAFM group. None of these characteristics were present in patients in the AFM-ad group. To further refine the rAFM case description, a blinded independent neurologist reviewed randomly selected cases, and the description was updated based on this review.

The researchers found that 34 patients had a diagnosis consistent with rAFM while 11 patients had a diagnosis classified as AFM-ad. The most common alternative diagnoses for the AFM-ad patients were transverse myelitis and spinal cord ischemia (spinal cord stroke). The researchers identified four major characteristics

shared by all rAFM patients. They also identified several key differences between rAFM and AFM-ad. These included differences in the pattern of limb involvement (rAFM cases were more likely to have an asymmetric onset and less likely to have both legs affected). rAFM cases were more likely to have decreased muscle tone, and less likely to have bladder and bowel issues, or sensory issues. AFM-ad cases were more likely to have an onset that reached its peak in less than an hour. rAFM cases were more likely to have an infection prior to the onset of symptoms. The researchers also found differing diagnostic and imaging characteristics between the groups. For example, rAFM cases were more likely to have gray matter predominant lesions in the spinal cord than AFM-ad cases.

The researchers suggest that their findings lend to a more well-defined case definition for AFM that should be used as a starting point for inclusion and exclusion criteria in research. Additionally, their findings may be used in the clinical setting to more quickly and accurately diagnose AFM, so that treatment can be administered immediately, and patients can be monitored for respiratory issues. Early diagnosis of AFM enables a better chance of identifying a pathogen in biological samples, and it may also provide prognostic information to guide long-term treatment and rehabilitation. While the researchers’ case definition of AFM may be useful in the clinical setting, it may be problematic for a small number of cases and should not automatically exclude all cases that don’t meet these criteria.

The authors of the study acknowledge that a major limitation of this study is the inability to independently validate the use of the proposed description of rAFM. Such validation would require a separate and prospectively defined cohort of children presenting with acute weakness including other pathologies, such as ischemic myelopathies. They also state that the criteria described is provisional and expect that an iterative process of refinements can better serve the research needs of the AFM community.

[1] Bove R, Werdal H, Olivera E. A Parental Perspective on Strengthening Knowledge After Acute Flaccid Myelitis. *JAMA Pediatr.* 2018 Nov 30.

[2] Hopkins SE, Elrick MJ, Messacar K. Acute Flaccid Myelitis—Keys to Diagnosis, Questions About Treatment, and Future Directions. *JAMA Pediatr.* 2018 Nov 30.

[3] Elrick MJ, Gordon-Lipkin E, Crawford TO et al. Clinical Subpopulations in a Sample of North American Children Diagnosed With Acute Flaccid Myelitis, 2012-2016. *JAMA Pediatr.* 2018 Nov 30.

A Parent's Perspective on AFM

By Rachel Scott

As a parent, we're always never satisfied with the present. We wistfully look at our baby's pictures and remember those gummy smiles, those first steps, sending them to kindergarten. We sagely tell new mothers, holding their bundled babies, that it goes so fast. And it does. We look back with nostalgia on those days — and at the same time we wish for time to speed up. We long to be done with diapers, to have all the kids in school, to not have to help anyone with their buckle. And for most parents, their lives travel along a predictable track. Their children go from helpless little babes, to reckless toddlers, to independent children. Just like they are supposed to. But sometimes, those things get interrupted and deviate from the course. A million different things derail the life we assume we'll have. A down syndrome diagnosis. A congenital heart defect. Limb differences. Cancer. Autism. For us, it was Acute Flaccid Myelitis (AFM).

Our perfect, silly five-year-old was paralyzed from AFM, a polio-like disease, over the fourth of July in 2016. He went from a ball of energy--always moving--to a still, quiet child. Intubated and tube fed. Unable to breathe or swallow or move at all — save his left hand. We didn't know or understand anything about AFM. Doctors had only given this diagnosis a formal name a few years earlier, in 2014. No one could tell us what his recovery would be like. After a few weeks in the ICU, we kissed his sweet neck and sent him away to have a hole cut in his airway for a trach and in his belly for a G-tube. Very real, physical reminders that our lives would never be the same. Within months, we were ordering wheelchairs and braces and equipment and learning about how to feed Braden and move him and rehabilitate him. Our lives bore almost no resemblance to how they were before. We dropped everything — cancelled trips to Disney, family reunions. My nine-month-old had to learn to take a bottle when I moved to a rehab facility five hours away with Braden.







I carried him out of the house when we went to the emergency room that July day — and I never would have believed it would be seven long months before he'd be back home. And that when he did come home it would be by ambulance, with 24/7 nursing care. It was heart-wrenching trying to figure out how to include him in our lives again. Eating and playing tend to be the basis of our social interactions — how do you include a child who can't eat at mealtimes or at birthday parties? Children are always on the move — they flit around from room to room and are always running. Braden can't keep up. He spent his kindergarten year in a hospital. He didn't attend any school — but his sweet school included him in the kindergarten graduation ceremony anyways. That sweet moment you assume will be yours — watching a tiny child wear a cap and gown on a stage — warped into some entirely different moment. Braden drove up to the stage in his powerchair and was supported by his dad as he tried to walk across. Caring for his emotional and social well-being occupied as much mental space as his physical wellbeing.

We've maintained a rigorous therapy schedule at home — walking on the treadmill, riding the functional electrical stimulation (FES) bike and countless other activities. He's done a thousand hours of electrical stimulation to try and keep his nerves and muscles alive. We've done a nerve transfer to hopefully help his hand work again. Taken out his tonsils in hopes that he'll breathe better. Had a professor build him a robotic arm to pick up his tiny bicep flickers and help move his arm. Doused him with essential oils. Tube fed him organic, plant-based food and vitamins and supplements. My mind is always focused on what we can do to give him the very best chance at recovery. We're hopeful that one day science will catch up and there will be stem cell therapies to help him heal and vaccines and treatments that prevent another child from this fate.

To that end, the parents in the AFM community have become a powerful network of advocacy and resources for one another. We have a very active Facebook group that is a wealth of knowledge. In almost any given medical appointment, the physician will not have treated a patient with AFM before, so the parents end up becoming huge advocates for their children. AFM tends to run in a two-year cycle — cases peak in the fall of even-numbered years. 2018 was a terrible year, and we all watched case after case join our group

and relived those painful, scary days in the ICU. In November, a group of approximately 15 parents went to DC to meet with legislators and sit down with the deputy director of the Centers of Disease Control and Prevention (CDC) to talk about their management of AFM. In December, three parents were invited by the CDC to come to Atlanta to present a parent's point of view on their AFM Task Force. It was such an honor and such a moving experience to be part of these groups. We know that our efforts are saving lives. Increasing awareness of AFM should lead to quicker diagnosis and better treatment. More funding for AFM will provide research for best practices for acute management, nerve transfers, rehabilitation and so much more. We've recently formed a non-profit, the Acute Flaccid Myelitis Association (AFMA), that is focusing on supporting and advocating for children and adults affected by AFM. The AFMA is excited to work alongside the TMA in improving the quality of life for those diagnosed with AFM.

I never would have dreamed that this would be my life — that I'd be a special needs mom. I've memorized his breaths. I watch him like a hawk and desperately try to anticipate every curveball we're thrown. We've cried harder than I ever thought possible. We've grieved the future we won't have for our child. But we've been so blessed to be on the frontlines of this disease and to help gain momentum in preventing more children from paralysis in the years to come. Braden is a warrior — he never complains. He's always ready with a joke. He's not scared of the future. I've learned so much from him.



Clinical Studies & Trials

For detailed information about clinical studies and trials, please visit bitly.com/tma-clinical-trials

1 **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

2 **Efficacy and Safety Study as Monotherapy of SA237 to Treat NMO and NMOSD**

Study Sponsor: Chugai Pharmaceuticals
This study is currently not open for recruitment.

3 **A Double-masked, Placebo-controlled Study With Open Label Period to Evaluate MEDI-551 in NNMO and NMOSD**

Study Sponsor: AstraZeneca/MedImmune/Vielabio
This study is currently not open for recruitment.

4 **Spinal Cord MRI Research Study for Children, Adolescents, and Young Adults with Myelitis**

Principal Investigator: Nadia Barakat, PhD
Study Site: Boston Children's Hospital

5 **A Longitudinal Study of Neuromyelitis Optica and Transverse Myelitis**

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

6 **The PREVENT Study**

Study Sponsor: Alexion Pharmaceuticals
This study is currently not open for recruitment.

7 **The TMA Registry**

8 Neuroimaging and Neurobehavioral Outcomes of Pediatric Neuromyelitis Optica: A Pilot Study

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

9 Utilizing Brain Imaging to Understand Cognitive Dysfunction in Transverse Myelitis

Principal Investigator: Lana Harder, PhD
Study Site: University of Texas Southwestern

10 Assessment of Pediatric and Adult Encephalomyelitis Related Outcomes: Understand, Reveal, Educate or APERTURE

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

11 Understanding Experiences with Vaccination Before and After a Rare Neuro-Immune Disorder

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

12 Neuromyelitis Optica, Anti-MOG Disease, Transverse Myelitis and Optic Neuritis Biorepository

Principal Investigator: Michael Levy, MD, PhD
Study Site: Johns Hopkins University

13 Phase II, Randomized, Single Blind Sham Controlled Trial Investigating Scrambler Therapy for Neuropathic Pain Caused by Neuromyelitis Optica Spectrum Disorder

Principal Investigator: Michael Levy, MD, PhD
Study Site: Johns Hopkins University
This study is currently not open for recruitment.

14 Pathology of Idiopathic Transverse Myelitis

Principal Investigator: Michael Levy, MD, PhD
Study Site: Johns Hopkins University

15 Upcoming Phase I human clinical trial using Q-cells in Transverse Myelitis

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



The Transverse Myelitis Association
Sanford J. Siegel
1787 Sutter Parkway
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Announcements

2019 TMA Quality of Life Family Camp: July 27 - July 31, 2019

2019 TMA 25-Year Anniversary Gala: August 24, 2019

Contact us

The Transverse Myelitis Association

PO Box 826962

Philadelphia PA 19182-6962

info@myelitis.org

855-380-3330

myelitis.org