the transverse myelitis association

newsletter

winter 2016

advocating for those with ADEM, AFM, NMOSD, ON & TM

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Find The Transverse Myelitis Association on Facebook! It is a great way to support The TMA and is a wonderful way to network with people in our community. Please take the time to become a fan of our page by clicking "Like," and tell your friends and family about our community's page. Facebook is a great way for us to raise awareness about these disorders and your experiences. Our link is *http://www.facebook.com/myelitis*.

THE EDITOR'S COLUMN

Sandy Siegel, PhD

The TMA ASAP Dollar-4-Dollar Matching Challenge launched in November 2015. A wonderful opportunity was offered to us through the Madison Charitable Foundation. The Foundation pledged to match every donation we received up to $80,000. Through this incredible generosity, The TMA set in motion plans to expand our support for the James T. Lubin Fellowship training of clinician-scientists focused on rare neuro-immune disorders.

Through the efforts of The TMA's staff and volunteers, a great campaign was designed. Roberta Pesce's work needs to be recognized in this regard. From creating the compelling video of Rilynn's story to designing the creative work both for publications and electronically, to implementing the campaign process, Roberta has put in an enormous amount of work and her creative efforts, as always, have been exceptional.

I've been doing The TMA work for over twenty years. The most challenging part of this effort is raising money. It is amazingly difficult work to do because it takes a lot of time and because asking people for money is never easy. This task and its difficulty isn't unique to non-profits; these conceptions about money are fundamental to American and western culture. During the early years of this work, I avoided the entire money issue. In fact, we decided very early on that we wouldn't have membership fees. We wanted no barriers for people to access information and support. I didn't ask members to contribute and I didn't ask family and friends. It quickly became obvious that avoiding dealing with money would mean that The TMA would never accomplish anything and our existence would be very short. It is more than naïve to think that you can run a not-for-profit and avoid asking people for money. Thus began my career as a fundraiser. Why? Because I know what needs to be accomplished, I have a good idea of the costs involved, and I am passionately driven to make people's lives better who have these rare neuro-immune disorders; starting with Pauline.

You don't necessarily become good at things you do for a long time; but experience doesn't hurt. I've definitely learned a lot. People support a cause like ours because they have suffered from the impacts of spinal cord, brain or optic nerve damage, or a family member has, and they want to hope that their life can be better. And because we are a compassionate people, we want other people going through these same experiences to have better lives as well. When an organization is young and growing, there usually aren't great accomplishments to show to 'prospective investors.' What you are selling in those early years is the potential for meaningful accomplishments and that there are people involved who can make those accomplishments happen. And donations in those early years reflected both; a hope for the future and a vote of confidence in the people who were doing the work. The donations most often were small. Wise investors want to see more than potential return on their investments.

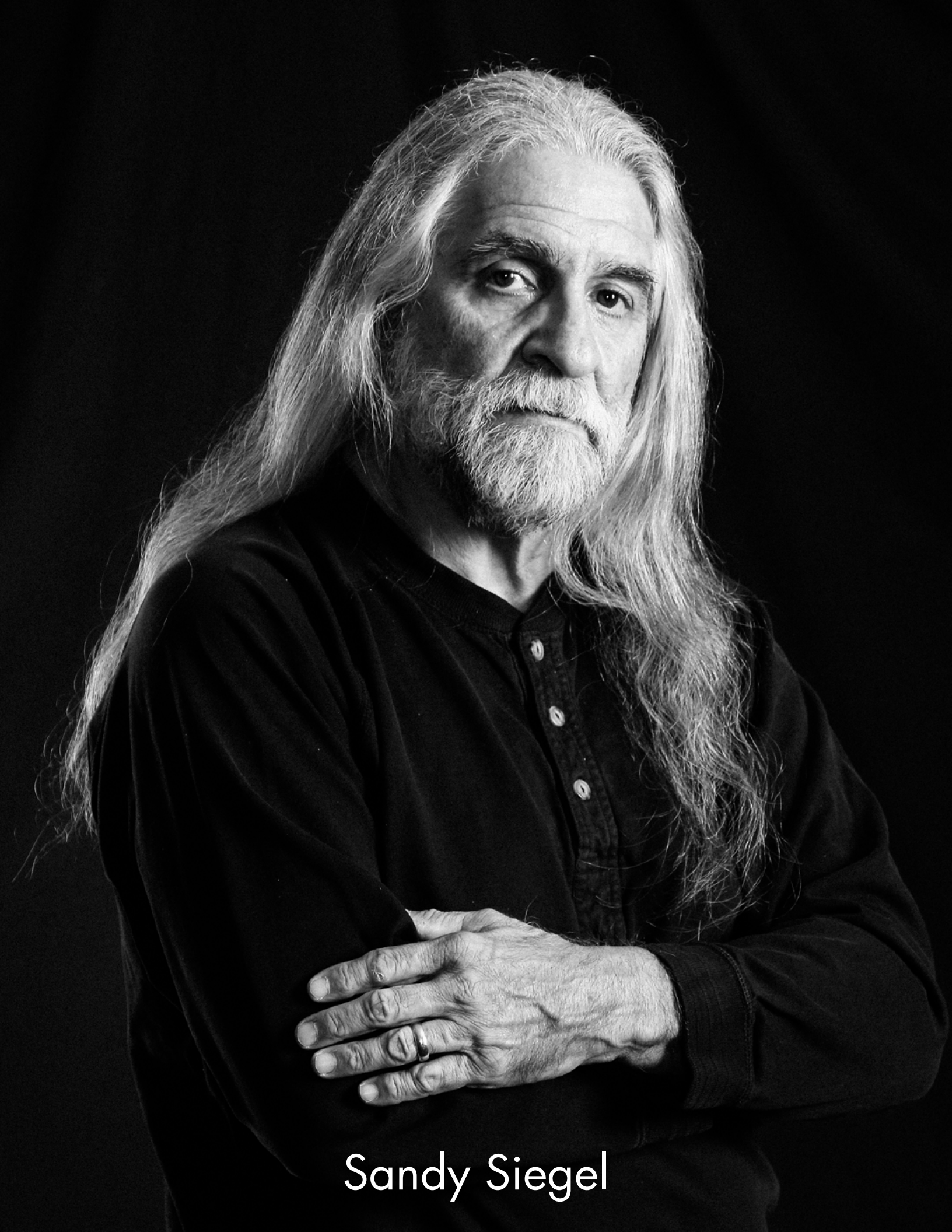
I've lost my discomfort about asking for money. I am so proud of the work we have accomplished. I am so proud of the organization we have created. I have no issues whatsoever asking people to support what we do and how we do it. We know that we have so much work in front of us, but we are now in a much better place to demonstrate to investors that our organization can deliver on our goals, and that we are so much more than potential. Having real, meaningful and growing accomplishments is fundamental to the fundraising process.

Over the years, the organization has had three important goals in our fundraising process. First, we needed to expand our base of support. Over most of the years of our existence, there have been around the same 400 individuals or families who were supporting the work to benefit the thousands of our members worldwide. This is just not a sustainable formula. Another goal was to encourage people who could do more to do more. These neuro-immune disorders are indiscriminate in their impact; our community reflects all economic backgrounds. Finally, in order to accomplish all of what we need and want to achieve, The TMA needs to get more people asking family and friends for support. First, we know that having a significant disability often means financial struggles for people. So many of our members are just not able to do very much or anything to support our efforts. But everyone has family and friends who support all kinds of wonderful causes. We need for our members to be proud of and passionate about our cause and willing to make the case to those around them that their support can make a meaningful difference in their life. We need to make it personal to our family and friends.

The ASAP Dollar-4-Dollar Challenge was a resounding success on all of these fronts. Through both online and check donations, we met the Madison Charitable Foundation match goal on December 15th. We had raised the $80,000 that would be matched by The Madison Charitable Foundation. And as an incredible gesture on the part of the Linda and Bob Malecky and Norma and Tom Petrosewicz families, an additional $25,000 match was offered to extend the value of the ASAP Challenge to fund the James T. Lubin Fellowship. On December 31st, that second goal was reached. The ASAP Challenge has raised over $181,959, a 127% increase compared to the initial goal of $80,000, and a total of $261,959 with the matching grant from The Madison Charitable Foundation to support The James

Thank
You

#ASAPCHALLENGE



Sandy Siegel

T. Lubin Fellowship.

Thank you to the 649 individuals and foundations who supported the ASAP Challenge.

This fundraising effort was a great success because of the support it makes possible for the fellowship, and also because it bodes well for The TMA's future; achieving our goals and making our mission a reality.

I stood on a stage at the opening of our symposium in Seattle in 2008 and announced the James T. Lubin Fellowship. It was important for me to do this in Seattle, because I wanted to be able to make this pronouncement while Jim was in the room with me and his community. Jim and Helena were in the back of the room as I explained why this fellowship was so important and why naming this fellowship for Jim was such a wonderful way to recognize all of Jim's contributions to our organization and community. In 2008 while I spoke these words, I didn't have the slightest idea how we were going to fund this fellowship, and I knew it would be expensive. But I also knew that this fellowship was critical for us. If you never create the opportunity, it sure isn't going to materialize out of thin air. Making it exist created the challenge for our organization.

It is 2015 and we have Dr. Allen DeSena and Dr. Michael Sweeney, and we have the funding for two more fellows. What a stellar achievement. No one in our community is confused about the dire need for more clinicians and researchers in the rare neuro-immune disorders. Dr. Kerr, Dr. Greenberg and Dr. Pardo have made great strides in training specialists, but it takes time and it takes funding. Our fellowship program will accelerate this training and development process by creating the funding necessary to attract the best candidates. And we have a process in place to ensure that we are funding the best candidates. The benefits for our community are direct and the most impactful. We want the best trained physicians caring for the people in our community. We have so much research that needs to be done, and training and developing researchers on these disorders is a fundamental part of the fellowship.

The TMA is so grateful for the generosity and support we've received from our community over the past month. Your efforts have been so inspiring and so appreciated! Pauline and I are personally thankful for all of what you do to support the work of The TMA. If a donation comes to The TMA, I am the person who opens the envelope. It's not easy for me, but I am going to try to describe what this experience is like for me. Whether it is a donation for $15,000 or for $5, I am entirely humbled by the gesture. I don't open these envelopes like a machine. I open them each like a human being, thinking and feeling about what it meant for the person or the family to decide to make that donation; the current of hope that runs through these gifts, the belief that by supporting this cause, their life can be better. Some of the writing on these checks is very difficult to read. I think about the paralysis or the spasticity or the pain or the fatigue suffered by that person every day, and what it must have taken for that person to pick up that pen to write the check, get it in the envelope, fix the stamp and get it into the mail. It's hard not to be touched and overwhelmed by all of it.

It is humbling and the sense of responsibility involved in accepting these donations is also very strong. I worked in a government job for more than 35 years. I understand something about the expectations that people have for workers who are supported by tax dollars. They are and they should be held to a different standard. That they don't often measure up is a problem – and an issue for a different column. I have also learned over the years that the expectations for people doing the work supported by good cause dollars are even higher; perhaps the highest there are in our society. This represents entirely voluntary giving, as opposed to what you pay in taxes, and the competition for these dollars is fierce. There are so many important and good causes and all worthy of your generosity. So, when the donations come to us, it is humbling. Your generosity makes it possible for us to work on your goals. It is a vote of confidence in our progress and our people, and we take it as such, and we feel the great sense of responsibility that comes with that vote. We all feel it. It drives us to work hard for you, and it motivates us to want to do as much as we can to improve your quality of life.

We can't thank you enough for making this campaign a great success. We thank you all from the bottom of our hearts.

Please take good care of yourselves and each other.

Photo Credit: Tiffany Burt

Understanding Cognitive Dysfunction

A study was recently published that looked at cognitive impairment in neuromyelitis optica spectrum disorder (NMOSD) in adults. The authors studied how cognitive impairment is related to the way the brain looks on imaging like MRI. The authors found that almost half (48.2%) of the study participants with NMOSD had cognitive impairment and had abnormal signals in the white matter and gray matter of their brain. Study participants with NMOSD who did not have cognitive impairment also had abnormal signals in their white matter, but not their gray matter. They also found that atrophy, or shrinking, of a part of the brain called the hippocampus was associated with cognitive impairment.

Liu Y, Fu Y, Schoonheim MM et al. Structural MRI substrates of cognitive impairment in neuromyelitis optica. Neurology. 2015 Oct 27;85(17):1491-9. *neurology.org/content/85/17/1491*

Dr. Lana Harder at UT Southwestern is conducting a study on cognitive impairment in pediatric transverse myelitis funded through TMA's partnership with Consano, a platform to enable individuals to donate directly to specific medical research projects and programs, advancing medical progress and empowering individual action. Dr. Harder is using MRI of the brain, optical coherence tomography, and neuropsychological testing to see if cognitive impairment is related to the way the brain and retina (a part of the eye) look.

For more information about Dr. Harder's study please visit: *bit.ly/consano*.

TMA at Disabilities Expo

Carol Carney

We were given the opportunity to spread awareness about The Transverse Myelitis Association and rare neuro-immune disorders at the Mobility Works 5th Annual Disabilities Expo in Tinley Park, IL on November 7th, 2015. Mobility Works, which sells adapted vehicles, has been a sponsor for the last two TMA Illinois Walk-Run-N-Roll awareness and fundraising events and generously offered a free booth to our fundraising committee at this year's expo.

Three committee members took this opportunity to set up the booth with The TMA banner, posters of patients relating their personal stories of their disorders, and loads of materials about the association.

It was a welcome surprise for four attendees in particular, who visited our booth, because they had never talked to or met others who had TM nor had they heard of the association. The sharing of information was a positive experience for everyone. Each of the four eagerly gave their names and their preferred method of communication so they could be included in receiving important and up-to-date information from The TMA. At the end of the day, the committee members decided that it was a day well spent and they would definitely take the opportunity to do it again. We were reminded of how many people are still out there who have these rare neuro-immune disorders The TMA advocates for and who need to know about the association and the benefits of belonging to The TMA.

We don't want to lose you

Please keep us informed of any changes to your mailing address, your phone number and your email address. You can send changes by going online to *tinyurl.com/bswg6yp* or via email at *info@myelitis.org*.

For those of you who wish to receive our communications by postal mail, the Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States and our territories and protectorates.

We save a considerable amount of money by doing our mailings this way. Unfortunately, when you move and don't provide us with the change, our mail will not be forwarded to you after your grace period, and this class of mail is not returned to the sender.

The cost to the Association is substantial. These are wasted printing and postage costs. Please keep your information current. Your diligence is greatly appreciated.

My Experience at the 2015 Rare Neuro-immune Disorders Symposium

Courage. I always think of courage when I see patients and families living with chronic disorders. You see, I come from an acute care nursing background. I think of myself as an ex-ER nurse; gun shots, broken arms, and illnesses; I couldn't know possibly what the diagnosis is. I just know something is horribly wrong and I need to get them to the providers who will take care of them. I know I must have seen acute transverse myelitis as an ER nurse. Back then, I knew I needed to get them to the right providers, right away. A short hour or two of my life until someone else will take my place in their care. I never knew what happened to anyone when they left the Emergency Department. I was never exposed to the courage of these families and patients. I would never be able to warn them of the type of tenacity it takes to live with a rare neuro-immune disorder for them and their entire family.

Fast forward ten years. My ER nurse days are long behind me. Through a series of left turns, I find myself as a rare neuro-immune disorders research nurse. I am the lucky one who will meet you from the day you're admitted to the hospital to the day you no longer need me. If that is one year or 25, fine by me. It's my pleasure to be a part of your courageous life. Up until now, that has been in a pediatric environment of a teaching hospital in Dallas. And then came the 2015 Rare Neuro Immune Disorders Symposium.

On October 23-24th 2015 in Dallas Texas, I attended the 2015 Rare Neuro-immune Disorders Symposium for patients and families hosted by The TMA, University of Texas Southwestern/Children's Medical Dallas and Johns Hopkins Transverse Myelitis Center. Again, I thought only one thing over and over again: Courage.

The courage it takes for one man to have a vision about improving the lives of children and adults with TM about 21 years ago.

The courage it takes for a researcher to say: I really want this study to help improve their lives and this is how I need to ask the community for their help.

When all other experts in the field say: "You are barking up the wrong tree;" the courage it takes to stand in the face of opposition and say "have an open mind and let us see."

The courage it takes to admit that disorders like TM, NMOSD and ADEM have left you with deficits and the courage to overcome them slowly.

I met many people from all over the world in two days who have rare neuro-immune disorders in common. I learned practical topics to help my neuro-immune community, both on an individual basis and the population as a whole. I participated in guided imagery as a relaxation technique. I learned the value of a group therapy session as a caregiver for a loved one.

I also learned about future research topics and brainstorming about better strategies to reach our rare neuro-immune community.

I learned the meaning of courage because I visited, for even five minutes with so many people connected with a goal to conquer rare neuro-immune disorders: NMO, TM, ADEM, ON.

Peace.

Patricia Plumb, RN, MSN, Senior Research Nurse at University of Texas Southwestern

An Update on the James T. Lubin Fellowship Training

FROM THE DESK OF DR. MICHAEL SWEENEY
UNIVERSITY OF UTAH MEDICAL CENTER

My training has progressed well through my fellowship here at the University of Utah! We have had quite the busy winter and have been seeing many patients with complex immune-mediated neurologic diseases. It has been invaluable having the opportunity to present difficult cases in our neuroimmunology conference and get ideas and feedback from providers with very different backgrounds and experience. We have been working with other team members in rheumatology, pathology, gastroenterology, oncology, immunology and neuroradiology to offer a truly multidisciplinary approach. From a training perspective, this has given me a lot of insight as to how different subspecialties approach similar issues, and how I might continue to integrate these approaches to effect the best patient outcomes in my future practice.

Research projects are also in full swing. We have been working to start our outcomes study in children who have been diagnosed with immune-mediated disease of the central nervous system. We completed the necessary research approvals and all of the patients have been identified; we will next be performing neuropsychiatric testing to help us measure neurologic outcomes. This will hopefully allow us to recognize subtle deficits that may be overlooked on routine examination in these patients, and ultimately to customize more beneficial treatments.

We have also been working to study transverse myelitis in the national veteran population. By characterizing etiology, treatment and outcomes in this large and diverse population, we will be able to identify areas for improvement in several aspects of TM diagnosis and treatment.

I am excited to complete my training this coming summer. I look forward to continuing to work with The Transverse Myelitis Association so that we may continue to make advances in the field and improve outcomes in those who are affected by myelopathy and myelitis.

Thank you,
Dr. Mike Sweeney

James T. Lubin Fellow Dr. Allen DeSena in Cincinnati, OH

Did you know that the very first James T. Lubin Fellowship recipient, Dr. Allen DeSena, has established a neurology practice at Cincinnati Children's and is accepting new patients, both children and adults?

Dr. DeSena trained under Dr. Benjamin Greenberg at the University of Texas Southwestern in Dallas from 2012-2014, at the TM and NMOSD center, and has expanded the reach of expertise in the rare neuro-immune disorders to the Great Lakes and Midwest regions of the U.S. He is furthering the goal of the JTL Fellowship in training others, and reaching and caring for those with a rare neuro-immune disorder. For those in OH, MI, IN, PA, and KY, he's the specialist in your backyard!

If you or your child has been living with one of the rare neuro-immune disorders, and need to be followed by a neurologist, or perhaps you are seeking another opinion from a neurologist experienced in these disorders, or you need to re-establish with a neurologist years after your diagnosis, please call Dr. DeSena.

It is important to maintain a relationship with a neurologist after an initial diagnosis or acute treatments have been administered, and even after significant recovery has been made. Should new or worsening symptoms arise, or anything of question a year or more out from diagnosis, many practices may require that you be re-established as a new patient. You may not need them often, but a neurologist, and particularly one trained in the rare neuro-immune disorders, should be a significant member of your healthcare team. You want them to be familiar with you and your medical history.

Contact Information

For **pediatric** appointments, call Cincinnati Children's Hospital Medical Center at (513) 636-4222.

For **adult** appointments, please call the Adult Neurology Clinic of UC Health Physicians at (513) 475-8730.

Allen DeSena

Animal Models To Study NMOSD and TM

Original publication: Bettelli E, Baeten D, Jäger A, Sobel RA, Kuchroo VK. Myelin oligodendrocyte glycoprotein–specific T and B cells cooperate to induce a Devic-like disease in mice. *J Clin Invest. 2006;116(9): 2393-402.*

Clinicians and scientists use a variety of tools to study rare diseases. Collecting data and specimens from patients is critical to understanding TM and NMO, but to understand the basic biology of a condition, scientists commonly use animal models of the disease. To date, there are no accepted animal models of idiopathic transverse myelitis (TM) or neuromyelitis optica spectrum disorder (NMOSD). For decades, however, there has been an experimental model of multiple sclerosis called experimental autoimmune encephalomyelitis (EAE). This model is imperfect and does not completely replicate MS, but has been useful for a variety of experiments. In humans, MS, TM and NMOSD are thought to be caused by an immune system that targets the brain, optic nerve or spinal cord by accident. In EAE, a mouse's immune system is primed to target the brain, optic nerve or spinal cord. In humans, different parts of the immune system (for example B-cells and T-cells) play critical but variable roles in the pathogenesis of MS, TM and NMO.

EAE can be triggered by immunizing mice with myelin antigens[1]. Antigens[1] are anything that triggers the immune system to produce antibodies[2] against it. The antigens[1] that target myelin used in EAE include myelin basic protein (MBP), proteolipid protein (PLP), and myelin oligodendrocyte glycoprotein (MOG). EAE causes demyelination in the brains and spinal cords of animals. Traditionally, studies have indicated that T-helper cells[3] are a key component in EAE, but it is unclear the role B-cells[4] play in EAE. In mice, when stimulated, there tends to be activation of T-cells or B-cells, but there is usually not a strong activation of both simultaneously.

Definitions (from NIH)

[1] **Antigen** An antigen is any substance that causes your immune system to produce antibodies against it. An antigen may be a foreign substance from the environment, such as chemicals, bacteria, viruses, or pollen. An antigen may also be formed inside the body, as with bacterial toxins or tissue cells.

[2] **Antibodies** An antibody is a protein produced by the body's immune system when it detects harmful substances, called antigens. Examples of antigens include microorganisms (bacteria, fungi, parasites, and viruses) and chemicals. Antibodies may be produced when the immune system mistakenly considers healthy tissue a harmful substance (autoimmune disorder).

[3] **T cell** T cells are a type of lymphocyte. Lymphocytes are white blood cells. T cells help the body fight diseases or harmful substances by attacking cells that have been tagged with antibodies.

[4] **B cell** B cells are a type of lymphocyte. They make up part of the immune system. B cells work chiefly by secreting substances called antibodies into the body's fluids.

In their 2006 article, Bettelli et al described a mouse model that triggered EAE in a majority (59%) of mice with B-cells[4] and T-cells[3] that were MOG-specific. In this model, unlike others, BOTH strongly primed B and T cells were generated in the mouse simultaneously. To get this mouse model, mice expressing T-cells[3] that target the myelin antigen MOG were crossed (bred) with mice that have B cells[4] that produce antibodies against the myelin antigen MOG. These crossed mice developed EAE on average 44.1 days after birth and the mortality rate was 10%. Furthermore, this mouse model showed more inflammatory lesions that were concentrated in the spinal cord and optic nerves. These mice had inflammatory lesions in the spinal cord and optic nerve, but not the brain, which mimics the lesion pattern seen in Neuromyelitis optica spectrum disorder (NMOSD). In this mouse model T-cells[3] and B-cells[4] cooperated to create this NMOSD-like disease. The MOG-specific T-cells[3] helped produce a large amount of a MOG-specific antibody[2], and the MOG-specific B-cells[4] helped the T-cells[3] propagate and activate.

The authors stated that the combination of the increased production of the antibodies[2] and the MOG-specific T-cell[3] response might have created the EAE in the mice. It is also unclear why these mice developed an NMO-like lesion distribution, but the authors noted that there was more MOG RNA in the optic nerve than in the spinal cord, and more MOG RNA in the spinal cord than the brain, which may account for why lesions are located in the optic nerve and spinal cord in this model.

This article describes a phenotype in a mouse that looked eerily similar to NMO, but was not based on anti-Aquaporin 4 pathology (the proposed model of disease in NMO). Since its publication there have been articles documenting an NMO-like phenotype in humans with anti-MOG antibodies. Thus, while this mouse model may not be applicable to patients with anti-AQP4 antibodies, it may be useful to model an NMO-like disease that is based on a different antigen. What this model reminds us about is the ability of two different patients (or animals in this case) to have very similar conditions, but different causes. This will be true for NMO, TM and even MS. Animal models are useful for numerous things. Developing a reliable model for TM will be helpful in advancing the field.

Comparison of Relapse and Treatment Failure Rates Among Patients With Neuromyelitis Optica:

Multicenter Study of Treatment Efficacy

Mealy et al. published a retrospective study comparing the relapse and treatment failure rates of three immunosuppressants (azathioprine, mycophenolate, and rituximab) used to treat neuromyelitis optica spectrum disorder (NMOSD). People with NMOSD have attack(s) of optic neuritis, transverse myelitis that extends more than three vertebral lengths, and around 70% of those with NMOSD are positive for aquaporin 4 antibodies. Patients were included if they had received azathioprine or mycophenolate for at least six months, or rituximab for at least one month, and patients who switched drugs were also included if they met these criteria. The authors defined treatment failure as "any new inflammatory central nervous system event that occurred despite immunosuppressive treatment." They also defined relapses "as new CNS symptoms and signs that lasted longer than 24 hours with or without an associated new lesion on gadolinium-enhancing magnetic resonance imaging." They defined treatment regimens as "optimal" or "suboptimal" so that they could see whether treatment failure was because of suboptimal treatment or occurred regardless of optimal treatment. Annualized relapse rates (ARRs) were calculated and included the number of relapses per year. This was an uncontrolled, retrospective study which has significant limitations.

Azathioprine: 32 patients were treated with azathioprine and prednisone. 53% of patients had at least one relapse during treatment. The ARR before treatment was 2.26, but decreased to 0.63 after treatment, which is a reduction of 72.1%.

Mycophenolate: 28 patients were treated with mycophenolate. 36% had at least one relapse during treatment, and 25% on optimal dosing had at least one relapse. Overall, the ARR before treatment was 2.61, but decreased to 0.33 after treatment, a reduc-

tion of 87.4%. The ARR before optimal treatment was 2.55, but decreased to to 0.25 after treatment, a reduction of 90.2%. Thirteen patients were also treated with prednisone, but six of the relapses occurred in patients treated with both mycophenolate and prednisone.

Rituximab: 30 patients were treated with rituximab. 33% had at least one relapse during treatment, and 17% of patients on optimal dosing had at least one relapse. Overall, the ARR before treatment was 2.89, but decreased to 0.33 after treatment, a reduction of 88.6%. The ARR before optimal treatment was 3.25, but decreased to 0.20 after treatment, a reduction of 93.9%.

Mixed treatment: 18 patients started on one drug and were switched to another. In 22% of these patients both therapies failed.

All three treatments reduced relapse rates in these NMOSD patients, but when dosed optimally, and even not optimally, mycophenolate and rituximab decreased the relapse rate more than azathioprine. This finding is supported by another study. The authors stated that rituximab and mycophenolate can be very effective treatments for NMOSD. They recommend tht when mycophenolate treatment fails, these patients should be quickly switched to another drug. They also state that patients who experience treatment failure with two drugs may consider other experimental treatments such as cyclophosphamide, methotrexate or eculizumab.

Original research: Mealy MA, Wingerchuk DM, Palace J, Greenberg BM, Levy M. Comparison of Relapse and Treatment Failure Rates Among Patients With Neuromyelitis Optica: Multicenter Study of Treatment Efficacy. *JAMA Neurol. 2014;71(3):324-330.*

Florida Dinner and Auction & Walk-Run-N-Roll

It was November 2011 – our 10-year old daughter, Sarah, walked into our bedroom in the morning after she awoke and within 30 minutes collapsed in front of our eyes. Our already mentally challenged daughter, was now paralyzed and life had forever changed. We were told we were lucky that the acute onset was not in the cervical part of her spine or she may have needed permanent assistance to breathe. We were not feeling lucky. The world for our family changed that day and now we were faced with the everyday challenges of raising our paralyzed daughter. We tried to comprehend the doctor's explanation that currently there is no medicine or treatment plan available to heal this child or anyone else suffering from this disorder. We were told she could possibly walk with constant and consistent physical therapy, or she might not. Now, our mission has begun. We are asking that you join us on this mission, a mission to raise enough funds to keep The TMA financially secure to continue to pay for the ongoing research, to provide families with information and support and to continue to raise awareness for these rare disorders.

Dinner & Auction

April 29, 2016
6:00 pm - 10:00 pm

Heritage Isle Country Club
6800 Legacy Blvd
Melbourne, FL 32940

myelitis.org/event/2016-florida-dinner-auction

Walk-Run-N-Roll

April 30, 2016
8:00 am - 5:00 pm

Rotary Park
County Rd 3
Merritt Island, FL 32952

myelitis.org/event/2016-florida-walk-run-n-roll

First Ohio Walk-Run-N-Roll

We're excited to announce that the first TMA Walk-Run-N-Roll Awareness Campaign in Ohio will be held on Saturday, May 21, 2016 at the Coffman Park Pavilion in Dublin.

The goal of our first campaign is to increase awareness and raise funds for research and programs for individuals suffering from Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis optica spectrum disorder (NMOSD), Optic Neuritis (ON), and Transverse Myelitis (TM) and their caregivers. We would love for you and your family and friends to be at the Dublin Recreation Center to share in this wonderful event.

If you or a family member have one of these rare neuro-immune disorders, you have been on a difficult journey. Coming together as a community is a powerful emotional experience. You are not alone. Please do all that you can to join us for this important event. It is a great opportunity for you to meet others who understand your experience better than anyone; and you will be supporting your Association.

You must register to attend this event. You can also register any friends and family who will be coming with you. To begin your registration, please go to the link listed below. You will be given the options to set up a team for fundraising, to join an existing team, or to do fundraising as an individual. The work The TMA does is so important for all of us; please do what you can to help us make a difference for you and for the people in our community. We so appreciate your support!

Please considering asking the businesses that you support in your community to support your cause.

We look forward to seeing all of you in May!

Lauren Taylor, Chairperson | ltaylor@myelitis.org
Sandy Siegel, President, TMA | ssiegel@myelitis.org
Barbara Ferguson, Walk Planning Committee
Mark McCloskey, Walk Planning Committee

Walk-Run-N-Roll

May 21, 2016
9:00 am - 12:00 pm

Coffman Park Pavilion
5200 Emerald Pkwy
Dublin, 43017

myelitis.org/event/2016-ohio-walk-run-n-roll

Fighting the Real Fight

By Dennis P. Wolf

Almost 23 years ago today, I had my first attack of Transverse Myelitis. The medical experts didn't know much then and there was certainly not a TMA to learn from. My wife and I were pretty much in the dark save the guidance we received from my wife Elise's father who was a physician. That compounded the problem because speed is of the essence and it was two weeks before Stanford University found a path for me. By then I was a quadriplegic and literally fighting for my life. You know you are in trouble when the doctor comes in and advises your wife to "prepare the children, their father may not make it through the night" and you as the patient begin thinking that maybe not living would be a good option. But fortunately, reality set in and I developed a strength that would carry me to become who I am today.

Today I am 62 and a survivor of battles brutally fought. The first crisis was in December of 1992. I was 39, married to my best friend, Elise; we had three girls aged 4, 7 and 12, and I was on a successful path. I spent five months as an inpatient in four hospitals. While I had already been hit once by auto-

immune disease, having become a Type 1 diabetic several years prior, I was really quite healthy and was a jogger. The future looked very bright, but we should not assume all brightness for the future because as Forrest Gump said, "life is like a box of chocolates, you never know what you are going to get."

This is the first time that I have written about this, but let me tell you what I "got." I had been traveling a great deal and when returning from Japan and the East Coast I came down with the stomach flu, which is very rare for me. Within a few days, I was suddenly overwhelmed

My Hero

By Yael Wolf

When I was in first grade I woke up and my father was no longer my hero. How could he be? He didn't even have the ability to walk, let alone fly or stop time like other superheroes. My dad had returned to being an infant. He learned to crawl, feed himself, and sign his name on legal documents with an "X." Eventually, I learned that superheroes do not always save the world; they sometimes just recover from a terminal illness without a tear shed. And in learning this I became stronger.

He sat in a big white chair the first time I saw him after he had become a quadriplegic. He could not open his own mail, let alone hug his six-year-old daughter. I eased myself onto my father's lap, my heart beating fast in fear of this new image of my hero. I became the

Yael & Dennis Wolf

by a dysesthetic pain across my entire chest and was rushed to the hospital. The hospital took several tests, but concluded that it must be a chest virus and sent me home; twice. Within a couple of hours, we rushed back to the hospital because I was in distraught pain, wobbly, and my bladder had failed. I was then finally admitted to the ICU and by morning I was completely paralyzed. The damage was scattered beginning at C2 and all the way down. The MRI showed severe inflammation across the entire cord. Two days later, I was transferred to Stanford University Hospital in critical condition. I was put in isolation, because the hospital still didn't know what was wrong with me. I was actually not fully cognizant and was fading away. The pain was overwhelming down my entire spinal cord. There is "pain" and then there is nerve pain that only a spinal cord injured or burn victim knows. It was that pain. And it continued for several months.

After five weeks I was allowed to see my children. Elise was constantly by my side albeit with full gowning and only minutes at a time. She was and is my inspiration. During the day and evening she was at my bedside. At night and morning, she was at home providing the children with her calm and optimistic presence.
Today, when I explain to people who question why I use a cane, wobble, have a paralyzed left hand, and have to self-catheterize, I give them the clinical and PC- friendly response: "in 1992 I had a demyelinating disease. I was in the hospital for five months and a wheelchair for a year but broadly recovered." It's also not true. You move on, but you never really recover. You are forever changed.

adult; I opened my father's bills with his knife he always used to use to open his letters. My hero was now incapable of being the person I looked up to, or so I thought. Through my father's courage and determination, I found a new hero in my dad. Have you ever been afraid to sit on your daddy's lap? I was. I was afraid of this new person who sat before me. I had more capabilities than my thirty-nine-year-old father. These thoughts ran through my head like a freight train on the tracks. As I sat there, on my father's lap, I looked around and saw IVs coming from his hands and arms and an oxygen tube connected to his nose. Besides wearing the hospital outfit, he also wore a smile. I realized that on my father's lap was where I was supposed to be. He was still the dad he always was. He was still the same hero. My dad, in a wheelchair, wore a smile, not a frown. He kept his hopes high, and at that moment when I tore open his letters, I realized my father was still the person I looked up to.

I held my mom's hand, not wanting to let go in fear of having to sit on the big white chair with my dad. I could still walk, why couldn't he? Looking at the mail on the hospital table I said under my breath, "Mommy, I'm scared of Daddy. Let's come back when he's all better." Not knowing what to do, my mother shed a tear and pushed me closer to the man in the chair. The man smiled and took my hand. The spark in our palms put a smile on my little face and I then accepted this new person for his strength. He was still a very determined and capable man.

I awoke one morning not knowing what had happened. I felt that the man I called a hero could no longer fulfill the position due to the lack of strength in his spinal cord. Through my dad's illness and recovery, I learned that heroes come in all different shapes and sizes. I learned that courage and determination makes you a hero, not the ability to drive a fast car or chase away scary monsters under your daughter's bed.

You are supposed to take what you have learned

I remember the first time I was allowed to see my kids. My oldest daughter, Shoshana, was visibly overwhelmed when she saw me. I calmly told her to remember the story of FDR and that I was still the same father and that we were going to be fine. When she left, I broke down.

I remember my middle daughter, Yael, writing years later about what the impact was in her life (essay included). Yael wrote this when she was 17 years old and reliving what happened to her when she hadn't yet turned 7.

I remember our youngest daughter, seeing me in a wheelchair entering the house for the first time in five months saying, "You are not the boss of me anymore." I answered her, "Oh, Tali, we have a lot of work to do!" But what would you expect from a four-year-old who hasn't seen her father at home for many months and is now using a wheelchair.

I remember most vividly Elise coming in to talk to me a few days after the doctor told her to prepare the children. With tears in her eyes, she told me that the doctors think I will make it but will be in a nursing home. I responded, "I will dance at Shoshana's bat mitzvah." Her Bat Mitzvah was 11 months later and with Canadian crutches and a leg brace, I did just that.

But what never leaves me is the joy of taking what is given to you and holding it sacred. My lesson was that we are the sum-total of our courage. That the sanctity of life and the gift we have been given must be paid forward. As my mother used to say, "We need to be good better best, in the past and thread it into your present and your future. I have learned many things about life and about who I am through my family's life changing experience. I will never forget the years of recovery and the excitement when my dad saw his big toe move for the first time in months, when I saw him crawl for the first time in the physical therapy ward, and when he learned to walk again with his leg braces and crutches out in the hospital garden. The memories of building and un-building my father's wheelchair every time we got in and out of my mom's red 1989 Oldsmobile will travel with me throughout my life. I'll never forget those things, and I hope I never do. I take what I have experienced throughout my life and change the bad into the good by learning through my own history. And I have a great deal of compassion for those who overcome obstacles.

In first grade, I re-evaluated life. I was taught that the saying, "it can't ever happen to you" does not apply to anyone, because look, it happened to my family, it happened to me. Although after a year my father improved dramatically and is now a successful business man, it remains a defining moment in my life. I don't look back on 1992 with animosity; I look back and realize that this was all a positive outlook on my young mind. I learned very early that life is a privilege and not a gift; it can be ruined in one day and fixed in two. You just have to learn to triumph over your own destiny like my father did. You have to re-examine your life at every groundbreaking moment you endure to keep your life rolling and your future life in check. Learn from the past and the future will come easily. My dad is more than my hero now; he is my inspiration.

Thanks Dad.

Elise & Dennis Wolf

never let it rest, until the good is better and the better best."

I have had a truly remarkable life. As a disabled person, I have been CFO of several companies, have taken a few public and have served on eight public company boards as the audit chairman. My life has been full and wonderful. I was hit a second time with TM five years ago and was significantly weakened, but I'm still standing.

My life has been enriched by my wife, Elise. Here I am writing about myself and my courage and my iron will. But really, my rock has been my wife and best friend. In my Jewish tradition there are 36 holy people at any time who walk amongst us; Elise is one of the 36. She not only stands by me, she healed me and holds me up- holds us all up. She is my hero.

I look back at my life and realize that my life has been well lived. I don't wish anyone the pain, the PTSD and the struggles that we all must have, but I wish for them what they can become for fighting the real fight!

Subscribe to The TMA Blog

Have you read The TMA Blog (*myelitis.org/blog*) lately? We publish weekly stories and articles written by individuals living with rare neuro-immune disorders, caregivers and families, as well as leading researchers and clinicians. The blog covers a wide variety of relevant topics, including stories about your experiences living with a rare neuro-immune disease, clinical care and management updates, new research studies, TMA awareness and education program announcements.

You don't have to wait for the latest publication of The TMA Newsletter or try to remember to visit The TMA website in order to receive the most up-to-date information on research and findings in the field of rare neuro-immune disorders. It's easy to stay informed about the latest events, programs and activities of The Transverse Myelitis Association. You can have all of this information delivered directly to your inbox so you won't miss a thing! To receive a weekly email with our latest blog posts in your inbox, please go to *http://eepurl.com/xuoGr*.

180 Medical Scholarship

180 Medical is honored to have started a scholarship program to help those with transverse myelitis, acute disseminated encephalomyelitis, neuromyelitis optica, spina bifida and spinal cord injuries. Realizing the financial burdens that exist for many of the families affected by these diseases, 180 Medical developed the 180 Medical Scholarship Program to honor these young adults pursuing goals of higher education.

Eligibility

High School Seniors: To be eligible, a student must be a high school graduate (or graduating senior), and have been accepted to a two-year or four-year college in the United States. They must plan on attending school full time (at least 12 hours) in the upcoming fall semester, and they must have transverse myelitis, acute disseminated encephalomyelitis, neuromyelitis optica, spina bifida, or a spinal cord injury.

College Students: To be eligible, a student must plan on continuing to attend a two-year or a four-year college in the United States in the upcoming fall semester. They must attend class at least 12 credit hours a semester and have transverse myelitis, acute disseminated encephalomyelitis, neuromyelitis optica, spina bifida, or a spinal cord injury.

The Scholarship Award

Three $1,000 scholarships will be awarded to those who demonstrate perseverance, courage, good will, and have made the best of their condition. These are one-time scholarships (not annual). Applicants are allowed to apply in subsequent years.

Deadline

180 Medical will begin to accept applications January 1, 2016. All application materials must be postmarked by June 1, 2016.

Application Process

To be in consideration for a scholarship award, you must include the following:

- Application: *180medical.com/uploads/docs/scholarship.pdf*
- Physician's statement of diagnosis
- Most recent official transcript
- Document verifying acceptance by college (or current enrollment)
- Essay: pick an experience from your life in which you had to overcome an obstacle and describe how it influenced you today. 500 word maximum.

Send all materials to:

180 Medical
Attn: Scholarship Committee
5324 W. Reno, Suite A
Oklahoma City, OK 73127

Facebook

Join 180 Medical on Facebook to stay up to date with all of the scholarship news. They will announce scholarship winners on Facebook in July 2012.
www.facebook.com/180medical

Questions?

If you have any questions please contact *scholarships@180medical.com*

Announcing the 2016 TMA Annual Quality of Life Family Camp

We are excited to announce that our TMA Family Camp will be held Sunday, July 31 through Thursday, August 4, 2016 at The Center for Courageous Kids (CCK) in Scottsville, KY.

How to Apply?

Application is now open at bit.ly/2016-camp-app.

Step One: Online Application

1. Please complete the form for Family Retreat by going to *bit.ly/2016-camp-form*.

Select Transverse Myelitis Association Family Camp (July 31 to August 4) in the drop down menu for Camp Session Requested. If you do not immediately receive an email, then your Step 1 has not been submitted. After you complete Step 1, continue to Step 2.

Step Two: Print Application

2. Download and print the Family Retreat application from *bit.ly/2016-camp-print-form*.

Please complete the form, ask your physician to sign it and return to CCK by mail or fax at the address below:

The Center for Courageous Kids
Attn: Camper Admissions, 1501 Burnley Road, Scottsville, KY 42164; Fax: (270) 618-2902;
Phone: (270) 618-2912

Application Process

Step 1 and Step 2 application forms must be completed before an application can be reviewed.

International families will be reviewed and notified on an immediate, rolling basis prior to final review date. This is necessary for families to make the appropriate accommodations and meet requirements for international travel.

Round 1 review

CCK will begin immediate review of new families on a rolling basis in the order in which the completed applications are received. All other completed applications will be reviewed March 7, 2016.

Round 2 review

Applicants reviewed the week of March 7, 2016 will be informed of their acceptance in the order they are reviewed and accepted by March 14, 2016.

Completed applications received after March 14, 2016 will be reviewed on a rolling basis in the order in which they are received until 30 families are accepted.

Round 3 review

Remaining applications, after the first 30 applications will be waitlisted and reviewed beginning on April 4, 2016 based on availability of space and willingness of families to share space. The review of the waitlisted applications will be on a rolling basis in the order in which the completed applications are received. Families will be informed of their acceptance in the order they are reviewed and accepted by May 2, 2016.

Please note that CCK has 4 lodges with 8 dens in each lodge (with either 6, or 8 beds in a den), and more than one family can be accommodated in one den based on family size, diagnosis and age of children. Families may identify another family they would like to share with when submitting the application.

If your child has special needs, is in a chair and unable to stand and transfer, or you are unable to assist your child in making these transfers, please let us know on your application.

Eligibility

1. Families with children diagnosed with ADEM, NMO, TM, ON and Acute Flaccid Myelitis (AFM) who are 5 to 17 years are eligible to apply to camp.
2. Applications are welcome from older and younger children, who may be accepted on a case-by-case basis.
3. Up to two adults living in the same household as the camper may participate in camp
4. All applicants must be members of The TMA. Membership is free.

Arrival and Departure information

1. Families will receive detailed information about arrival and departure times along with their acceptance information from CCK. In general, most families arrive at camp around 3:00 pm on the first day of camp, Sunday, July 31, 2016. Camp closes at noon on Thursday, August 4, 2016.
2. The closest airport is Nashville, Tennessee. For help with ground transportation between the airport and camp, please contact The TMA at *tmakids@myelitis.org* with travel information. Please do not make plane reservations until you receive an acceptance letter from CCK.

Cost

1. There is no cost for families to come to camp besides personal travel expenses. The TMA and CCK have a partnership under which we cover the cost of camp.
2. TMA will be able to offer some financial help via travel grants to families. All accepted families will receive an email with an application form and guidelines to apply for this funding in approximately May, 2016. They are offered on a first come first serve basis until grant funds are no longer available.

Education Program

Medical professionals and specialists from our medical community will be joining camp and provide a three day education program for the parents and any of the children, teen or young adults who attend camp and are interested in the education program.

Special Requests

If your child has special needs, is in a chair and unable to stand and transfer, or you are unable to assist your child in making these transfers, please let us know in advance.

Clinical Studies & Trials

myelitis.org/trials


What if
your child
could
make a
difference?

The Transverse Myelitis Association
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Powell, Ohio 43065-8806

CHANGE SERVICE REQUESTED

Contact us

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Announcements

2016 TMA Quality of Life Family Camp: July 31 to August 4, 2016

Donate

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Powell OH 43065-8806
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