FIRST ANNUAL GOLF OUTING 2014
THE TRANSVERSE MYELITIS ASSOCIATION

Chippin' in against Transverse Myelitis

RECOGNIZING 20 YEARS OF SERVICE

Monday, September 29, 2014

Scioto Reserve Country Club | 7383 Scioto Parkway | Powell, Ohio 43065

Greetings!

Thank you for your time and interest in The Transverse Myelitis Association Golf Outing to be held in Columbus, Ohio on Monday, September 29, 2014. As patients, parents, caregivers, and family members of those diagnosed with Transverse Myelitis and other rare neuro-immunological disorders, we are committed to raising awareness and funds to support The Transverse Myelitis Association (TMA). Our goal this year is to raise $100,000 to fund research and to demonstrate our support to the many individuals and families who struggle with these disorders. We ask for your help in reaching this goal!

The TMA, founded in 1994, is a non-profit, 501(c)(3) organization (EIN 91-1780467). The TMA is dedicated to the support of children, adolescents, and adults with these disorders and their families. It is believed that a person who develops Transverse Myelitis, or the other rare neuro-immunologic disorders, likely has a genetic predisposition to auto-immunity, and that there are environmental factors that interact with these genetics to trigger the disease. The goals of the TMA are to advance a comprehensive network of medical professionals dedicated to the care of patients, to support research, and to develop new acute and regenerative therapies. The TMA currently supports approximately 10,000 members from more than 80 different countries and has a large number of support groups across the U.S. and around the world. There is no cost associated with becoming a member of the TMA.

Each of us on the TMA Golf Outing Committee has been impacted by these rare neuro-immune diseases. We decided we wanted to make a difference in our community by establishing this important awareness and fundraising campaign.

We sincerely ask for your thoughtful consideration in sponsoring our event to further advance the efforts and goals of the TMA. Your participation will be recognized at one of five sponsorship levels: Naming Sponsor ($10,000), Platinum ($5,000), Gold ($3,000), Silver ($1000), or Tee or Green Sponsor ($200).

The Transverse Myelitis Association needs and appreciates your assistance. We genuinely believe that with the funds we raise, we can increase awareness and accelerate research in the hopes to one day diminish or eliminate the life-altering effects of Transverse Myelitis and the other rare neuro-immune diseases. Please consider a sponsorship to help us reach our goal of $100,000!

On behalf of the TMA Golf Outing Committee and our families, we want to thank you for your consideration. We cannot achieve our goal without your help.

With our sincere thanks,
The TMA Ohio Golf Outing Committee

Sandy Siegel | ssiegel@myelitis.org
Erica and Josh Miller | ericajbush@gmail.com
Mark McCloskey | markmcclosk@yahoo.com

2014 TMA GOLF OUTING - SPONSORSHIP FORM
SCIOTO RESERVE COUNTRY CLUB SEPTEMBER 29, 2014

Company or Person(s) Names:	
Contact Name (if different than above):	
Street Address:	
City, State & Zip Code:	
Telephone Number:	
Email Address:	
We (I) would like to help in your efforts! Please count on us for a sponsorship level of:	Naming $10,000 Platinum $5,000 Gold $3,000 Silver $1,000 Tee/Green $200 Friends/Family $100
We (I) would prefer to help with a monetary donation of:	$________________
We (I) would like to help with a donation-in-kind of (e.g.: food/beverages, printed supplies, door prizes, etc.):	____________________ ____________________ ____________________
Would you like to receive additional information from The Transverse Myelitis Association throughout the year? (Please circle one):	Email Mail Not at this time

THANK YOU SO MUCH FOR YOUR SUPPORT!

Naming Sponsor: Two Sponsorships will be accepted. Name the outing: The COMPANY and TMA Golf Outing to Cure Neuroimmunologic Disorders: $10,000 – includes naming rights, signage on first tee box, recognition in commemorative brochure and the TMA Web site and social media sites, and two foursomes for golf outing.

Platinum Sponsorship: $5,000 – Name the Hole in One Contest or the Long Drive Contest or Closest to the Pin Contest, include sign on one tee or green, recognition in commemorative brochure and the TMA Web site and social media sites and two foursomes for golf outing.

Gold Sponsor: $3,000 – Sign on tee box or green, recognition in commemorative brochure and the TMA Web site and social media sites and one foursome for golf outing.

Silver Sponsor: $1000 – Sign on tee box or green, recognition in commemorative brochure, and the TMA Web site and social media sites and two golfers for golf outing.

Tee or Green Sponsor: $200 – Sign on tee box or green.

Friends and Family Sponsors: $100 – The Transverse Myelitis Association is a 501(c)(3) organization and contributions are deductible to the extent permitted by law.

Lunch donor: Recognition in commemorative brochure, the TMA Web site and social media sites and sign at distribution table for lunches.

Donor of prize items: Sign at registration table, recognition in commemorative brochure, the TMA Web site and social media sites.

Please mail the form on the previous page and your check payable to:

The Transverse Myelitis Association
1787 Sutter Parkway
Powell, OH 43065-8806

Or

Donate online via our Ohio Golf Outing website: **www.myelitis.org/golf-outing**

Or
Contact Us:
Sandy Siegel | ssiegel@myelitis.org
Erica and Josh Miller | ericajbush@gmail.com
Mark McCloskey | markmcclosk@yahoo.com
Chitra Krishnan, Executive Director, TMA | ckrishnan@myelitis.org | 1-855-380-3330

ABOUT THE TANSVERSE MYELITIS ASSOCIATION

The Transverse Myelitis Association (TMA) is a tax-exempt 501(c)(3) organization that supports people who suffer from the rare neuro-immune diseases.

What are these rare neuro-immune diseases? Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), Optic Neuritis (ON), Transverse Myelitis(TM) and Recurrent Transverse Myelitis are immune-mediated disorders of the central nervous system (brain, spinal cord and optic nerves). The disorders occur when a person experiences a sudden acute inflammatory attack in the spine, brain or optic nerve, with symptoms such as weakness, blurry vision, loss of sensation, bladder dysfunction. **These diseases affect individuals of all ages; approximately 25-30% of those affected are children** (depending on the disease).

What is the damage caused? Nerve damage caused by inflammation can result in many long term problems, which include blurred or lost vision, pain, sensory loss, bladder or bowel dysfunction, weakness resulting in disability and paralysis depending on the extent of the injury. Some people lose the ability to breathe on their own depending on the level of the attack in the spinal cord. Other common symptoms of these disorders include fatigue and spasticity.

THE GOALS OF THE TMA ARE:

- To create a comprehensive and dedicated network of patients, researchers and health care professionals focused on providing excellent care
- To advance our understanding of the causes and the natural history of these diseases
- To develop new acute and restorative therapies

YOUR DONATIONS WILL HELP THE TMA:

- Advocate for its more than 10,000 members from every state in the US and from more than 80 countries around the world

- Provide seed funding for the establishment of medical centers of excellence dedicated to the study and care of these disorders
- Fund national and international educational seminars
- Host quality of life camps for children and families affected by these disorders
- Educate individuals who live with these disorders and their families so they can better manage their medical care and form strong support networks
- Support the post-residency training of clinicians through the James T. Lubin Clinician Scientist Fellowship Award

SOME HIGHLIGHTS...

- From 2002 to date, the TMA has awarded over $470,000 to fund pilot research projects, research centers and clinical training (James T. Lubin Fellowship)
- The TMA has spent more than $300,000 to support symposia, camps, and other education programs
- We support two Medical Centers of Excellence– at Johns Hopkins University School of Medicine and at the University of Texas Southwestern – dedicated to the study of these rare neuro-immunologic disorders

RIDING HARD TO RECOVER THE ABILITY TO WALK

Those with transverse myelitis know the statistics. We are a rarity, a neurological oddity so to speak. But at the heart of all the scans, tests, poking and prodding is a person whose life was drastically changed in a day without a good explanation.

I would have bet that if I was going to be injured, it would have been on a bicycle. I was 45 years old and had just weeks before finished the Leadville Trail 100. The LT100 is a 100 mile mountain bike race all of which is above 10,000 feet; the toughest course in America according to some. I raced down mountain passes over loose rocks and gravel. I survived that unscathed.

Several weeks later, I went to bed not feeling well from some type of flu-like virus. We had just moved into a new house and boxes were everywhere. I called in sick for work (I am a veterinarian) for the first time in over 20 years. The first night in our new house I remember trying to get out of bed and doing a somersault into the dresser. My legs were too weak to support me. At first we thought that maybe I was just very weak and dehydrated. I scooted down the steps and my wife drove me to the ER.

After numerous tests and scans, they never could pin point an exact cause to what triggered my own immune system to attack my spinal cord. The official diagnosis: Idiopathic Transverse Myelitis. My neurologist says I was a little different from other TM patients she has seen because I was so systemically sick. I had a fever and my blood values were abnormal. Within a few more days, my left arm (I am left-handed) stopped working and I still could not move either leg. I soon stopped breathing on my own and was placed on a ventilator. While on the ventilator I developed pneumonia. A stomach feeding tube was placed and my overall condition could best be described as atrophy and decline. Blood pressure issues followed, and I would pass out as soon as sitting upright. Initially, besides the paralysis, there was a feeling of a rope around my middle being squeezed so tight you would think it was cutting through you. TM basically reduced me to the helpless state of an infant and I was dependent on other people for every basic need.

I have treated my TM recovery like training for an athletic event that never comes. When I came home from the hospital, I purchased a recumbent exercise bike. It would take me 20 minutes to get my feet into my cycling shoes which I left clipped to the pedals. I was so weak the bike would turn off even though I was pedaling. Each day, I logged my power wattage, time, and calories burned. Over the ensuing months I would continue to get stronger. Even though I couldn't take a single step, I wanted to ride my "real" bike. On July 4th 2011 I convinced my wife and sons to balance me on the same bike on which I rode the LT100 the previous summer. I had no idea if I would be successful so I started in the grass to break any falls. After a shaky start, I made it 5 miles. The actual ride is posted on YouTube under "Independence Day-TM Recovery." I truly thought that after one summer I would reward myself by going to France and ride my bike up a mythical cycling mountain pass called the Col de la Madone. Well, that didn't happen. My experience with TM recovery is that it is drip by drip no matter how hard I try. Despite the frustration of not being where I want to be, I realize I am fortunate to have improved as I have. Recently, my cycling friends arranged a special ride so I could experience the group rides I used to enjoy so much. We went 17 miles on the open road. I was painfully slow and very tired but grateful to be able to ride. I would still love to ride up the Madone; I just cannot say exactly when that will be.

Initially, I went back to work in a wheel chair. That transitioned to a walker, two crutches, one crutch, and eventually a cane. As I approach the three year mark of my TM attack, I have left the cane in the car and can walk short distances without it. I can now perform surgery and see patients and I am thankful I have a job I enjoy and can still perform. My hours are still reduced just due to general fatigue; some days are better than others.

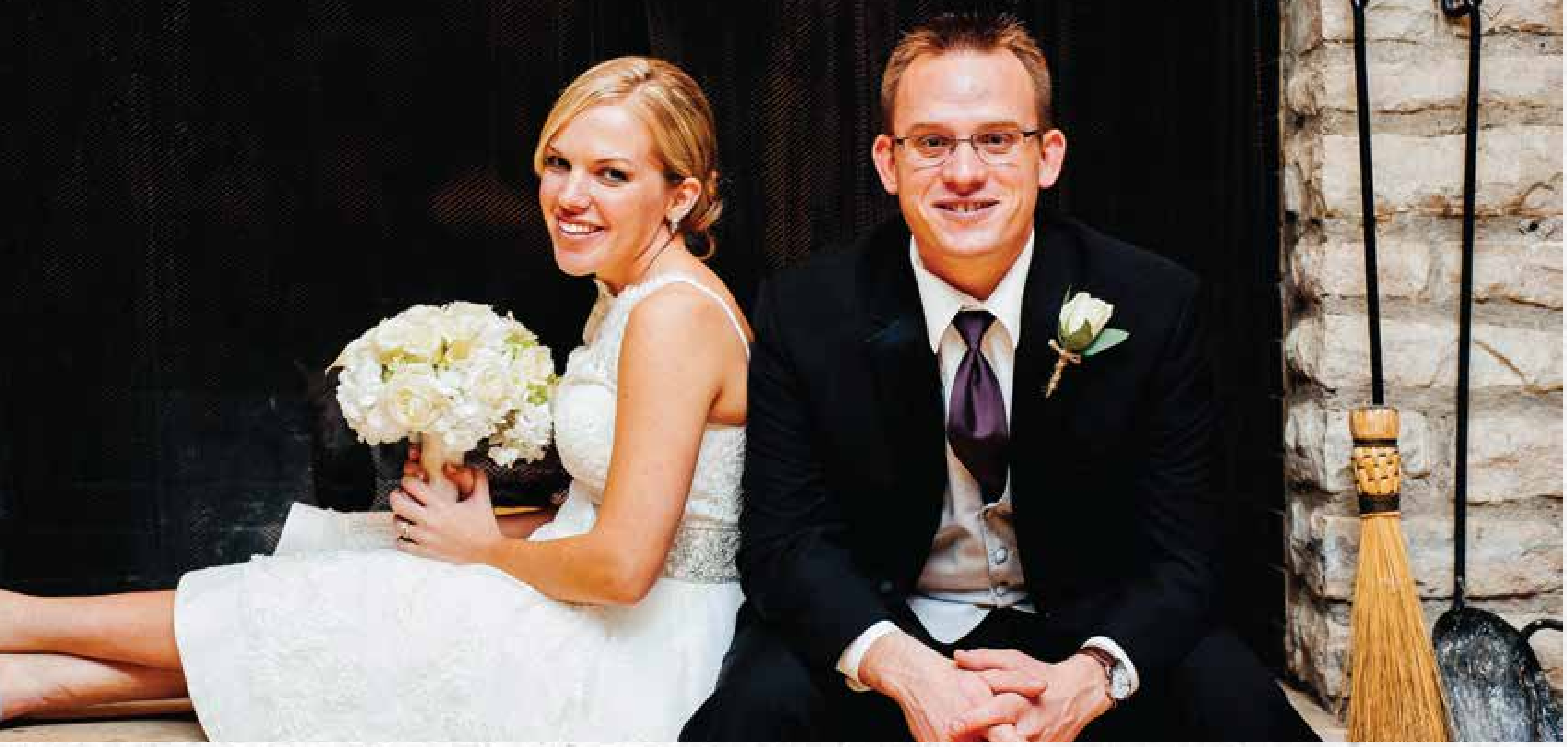
As a veterinarian, I am aware of many diseases that cross species, but transverse myelitis was not one of them. When I was in the hospital I googled TM and was stunned to learn that this rare neurological disease has an international organization based in my current home town of Powell, Ohio. I emailed The Transverse Myelitis Association, and Sandy Seigel called me later that day. Sandy has helped countless people and their families from all around the world deal with TM since his wife Pauline's TM attack nearly 20 years ago. Sandy started our conversation by saying, "I am sorry this happened to you." While I can't say anything good about TM itself, it does make us aware of the good already in our lives. I am very fortunate to have friends, family members, and co-workers who have been there for us. I lean heavily on the strength of my wife, Michele, and my two sons Michael and Kyle in dealing with the challenges brought on by TM.

The fact that we are so few in number moves TM patients down the "food chain" as far as research dollars go. If the research is going to get done, it needs to be pushed forward or even paid for by those who need it. This golf outing is part of that "push." The funds raised will go towards studies that could:

- Develop new treatments for TM attacks to limit the neurological damage
- Identify new procedures to repair the TM damaged spinal cord
- Study medications to help TM patients in their day to day lives
- Predict who is at risk for TM, and prevent it from ever occurring

Every contribution is greatly needed and appreciated!

~ **Mark McCloskey** is a 1990 graduate of The Ohio State College of Veterinary Medicine. He has practiced for 24 years and serves as Hospital Director for Beechwold Veterinary Hospital here in Columbus. He and his wife Michele have two sons, Michael and Kyle. They also share their home with three dogs: Dugan, Dora, and Casey. Mark currently serves on the Veterinary Practioner Advancement Board for the veterinary college and enjoys volunteering for Canine Companions for Independence. He has also recently volunteered for the Riverside Hospital Neuro-Rehab Patient Advisory Committee.



CREATING A NEW NORMAL AND WONDERFUL LIFE

For the past 27 years, I have faced physical and mental challenges every day of my life. My story is a bit different than most people diagnosed with Transverse Myelitis as I am someone that has lived with this disease my whole life. I have never known what it is like to be normal. Living with TM is my normal. My story is told after listening to those closest to me, my family, because I was too young to realize all of what happened to me as a baby.

Ten years to the day that my parents lost their first child to Spina Bifida, I became very ill as I was crawling and playing with my older brother at our home. At that time, my parents became very scared and knew something was not right. Away to the emergency room we went. In the beginning, my parents were told I suffered a concussion, but their hearts told them otherwise. After going home for the night, my mother had a gut feeling that I needed to go back to the emergency room as I was vomiting and was paralyzed from the neck down. Following multiple spinal taps, doctors were unable to figure out what went wrong as the results were coming back normal. Shortly after these tests, my respiratory system failed and I was then admitted into the ICU at Children's Hospital. It's the ICU where I lived for the next month and was referred to by the staff as the "Floppy Baby." It took an entire year for them to finally diagnose me with Transverse Myelitis.

My parents were repeatedly told that I would never walk. As parents, this scared them to think that their only daughter was going to be in a wheelchair for the rest of her life. God must have been on my side as he has been my entire life. Through the countless physical therapy sessions, I was blessed to walk. I may walk differently than most people and it may get some looks from others, but I walk. As a child and teenager I had multiple surgeries to repair my ankles and hamstrings and to try to mitigate the difficult pain. Before each surgery I was always under the assumption that after the surgery I would be "normal." Unfortunately, that has never happened. To this day, I am hoping for some cure and drastic surgery to make me normal and everyone else affected by TM.

Currently, I believe my life is pretty great. Just like everyone else, I have challenges, but I deal with them. I currently work as a mental health counselor in nursing homes around Columbus and love it. I believe my TM and the experiences I have had to endure put me in this position to help. In October of 2012, I married the man of my dreams, something as a teenager, I never thought would happen. As a teenager with a disability, I always thought no one would want to marry the girl with a disability. But I was lucky enough to find someone that did. In fact, even into adulthood I worry about my disability. On our wedding day, I wasn't sure if I was going to be able to walk down the aisle and many family and friends questioned it too. I gained the courage to walk down the aisle and it is one day I will never forget. Like I said earlier, I have challenges, some emotional and some physical. My physical challenges are mostly pain and lack of endurance. Through the use of botox, swimming and physical therapy, I pretty much have these issues under control. I handle the emotional challenges pretty well thanks to my husband and family.

Reflecting on my story, I realize how truly blessed and lucky I am. I am lucky enough to have limited pain and the ability to walk; however there are those out there that are not as lucky. This is one of the reasons I signed up to volunteer with the TMA. I want to be able to raise money for those individuals who are not as fortunate as I have been and hopefully find a cause and even valuable treatment options.

~ Erica Bush was born and raised in Gahanna, Ohio. She graduated from Gahanna Lincoln High School in 2005. She attended Muskingum University where she received her Bachelors of Science in Psychology. Erica attended The University of Dayton where she received her Masters in Counseling. Erica currently works as a professional counselor providing mental health services to those residing in extended care facilities. Josh was born and raised in Millersport, Ohio and graduated from Millersport High School in 2005. Like Erica, Josh attended Muskingum University where he majored in Criminal Justice. After college, Josh began working in the Insurance Industry and is currently an insurance adjuster for a large insurance company. Josh and Erica met in college and have been married for a little over a year. They currently live in Pickerington, Ohio with their dog, Stanley.

TRANSFORMING PERSONAL TRAGEDY INTO AN INTERNATIONAL OPPORTUNITY

I was a very healthy thirty-five year old kindergarten teacher living and working in central Ohio. At the end of July, 1994, I was getting better after a bout with the flu when I started to experience a backache. I never considered it anything more than a muscle ache, but these sensations went on for a week without getting better. On a Sunday night at the end of July, I was getting dressed after taking a shower, and fell to the floor with excruciating pain in my back. While I was lying on the floor writhing in pain, I thought about getting to the phone to call for help. At that moment, I realized that my legs were paralyzed. I was able to drag myself to a phone cord and pulled the phone down to me on the floor. I called Sandy who was with his family celebrating his father's birthday. I had stayed home from the party because of not feeling well. Sandy came home and got in touch with my doctor, who told me to get to the hospital. We called an ambulance and then spent nine hours with an emergency physician who was totally baffled about my condition. If you go into an emergency room with symptoms of paralysis and you didn't hit your head on the bottom of a swimming pool or experience a car crash, the diagnosis of the paralysis can be a challenge. Physicians do not learn very much or anything about transverse myelitis in medical school. As the emergency physician was determining that my symptoms were a figment of my imagination, it finally dawned on him that my bladder was very full and that I was totally unable to urinate. He found the neurologist on call. The neurologist had me admitted and started me on a high course of intravenous steroids. On the Friday of that week, I was told that I had transverse myelitis and was sent to the rehabilitation hospital at Ohio State. I had no motor function or bowel and bladder function below my waist. My sensory function was entirely impaired. I was in the rehab hospital for a few weeks before I had a return of movement in the big toe of my left foot. My return of motor function had begun and the return was amazingly slow and in very small incremental steps. I became the model for hard work, perseverance and determination at the rehab hospital. I was there for almost two months. I returned to our very much not accessible home and began outpatient physical therapy at the rehab hospital five days a week. Sandy went to work every day arming me with a telephone so that I could reach him in the event of an emergency, and an arrangement of chairs that allowed me to transfer through a narrow door from my wheelchair to the toilet. Only Rube Goldberg would have appreciated the set up. Every night, I would grab hold of Sandy around the neck and he would carry me up the flight of stairs to our bedroom.

I went back to teaching two kindergarten classes when winter break ended in January … from a wheelchair. I continued outpatient physical therapy three days a week after school through the rest of the year. Over a period of about eighteen months to two years, I experienced motor recovery that allowed me to walk with two canes using fisher grips. I also had some very complicated and difficult symptoms that never got better, including bowel and bladder issues, nerve pain and fatigue. My symptoms were fairly stable for a very long period of time. About two years ago, I experienced a significant worsening of my motor function. None of my doctors have been able to determine the cause, but I have lost the ability to walk with my canes and have become more reliant on my chair.

In a very remarkable way, my story of getting transverse myelitis is the story of The Transverse Myelitis Association. There isn't a good time to get a transverse myelitis diagnosis. But 1994 was most definitely a really bad time to get TM. There was no research and very little published about it in the medical literature. Neurologists knew almost nothing about it. There were no specialists and no medical centers focused on this disorder. There was no support network and there was no information about it that was available to a lay person. And there was no internet. For the first six months, we were like deer in headlights going through this experience. We were so ignorant that we had no idea just how little our doctors understood about what had happened to me.

Finally, through a publication of the National Organization of Rare Disorders, we found a family in Tacoma, Washington who had a daughter who got TM when she was 18 months old. Sandy made contact with this family, and through that phone call, The Transverse Myelitis Association was born.

Sandy and I have been on the most remarkable journey. While my life is filled with challenges, I am no longer going through this experience alone. The TMA has more than 10,000 members from more than 80 countries around the world. While so much remains a mystery about transverse myelitis, today much more is known, and through the TMA web site, publications and education programs, I have access to information that has helped me to be a much better advocate for my medical care. My medical care has improved and we now have a network of physicians around the world who do a wonderful job caring for people in our community. There are two centers of excellence in transverse myelitis and the TMA is funding a fellowship which is training the first physician to be a transverse myelitis clinician and research specialist. And while there is so much more work to be done, I have great hope from the potential of current and future research on transverse myelitis.

I have learned much from this experience. While there are many challenges, there is most definitely a good life after getting transverse myelitis. I have a wonderful family, including three beautiful grandsons. I haven't missed a year of teaching since I got TM and I am now a fourth grade teacher. And I have an exceptional and sweet companion that helps me every day ... besides Sandy. In August, 2006, I went through team training at Canine Companions for Independence, and was matched with the most incredible service dog, Kazu. Kazu has become my best and sweetest friend, loyal companion and most dedicated support one could possibly imagine.

TM is a very rare disorder. My hope for the future is fueled by the kind of fundraising that we are working so hard to support. Your support of our efforts gives me great hope, and it offers hope to the mother of a 4 month old child who gets TM and to a middle aged woman in Kansas who is diagnosed with TM or to an 80 year old man in Florida who is diagnosed with TM. We are all working hard to make our lives as good as they can possibly be, and we so appreciate your consideration of helping us in our great cause.

~ **Pauline Siegel** was born and raised in Coshocton, Ohio. She received her BA in education from Capital University. She received her Master's Degree in education from The Ohio State University. She has been an elementary school teacher in the Worthington School District for more than 23 years. She has taught kindergarten, second and third grade. She is currently a fourth grade teacher. Sandy was born and raised in Cleveland. He received a BA in anthropology from Miami University and a Masters and Doctorate in Anthropology from The Ohio State University. He has been an instructor at Ohio State, Franklin University and Capital University. Sandy worked for the Public Utilities Commission for more than 31 years and is currently retired from the State of Ohio. Pauline and Sandy have two married sons, three grandchildren, and one on the way. Their sons and daughter in laws are all graduates of The Ohio State University. Pauline and Sandy helped to establish The Transverse Myelitis Association shortly after Pauline got TM in 1994. They have been doing this work as volunteers for almost 20 years. Sandy serves as the President of the TMA.