



The Transverse Myelitis Association

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NEWS RELEASE

Transverse Myelitis Awareness Day, June 6, 2000

The Transverse Myelitis Association

State of Ohio

Columbus, Ohio

USA

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Date of Release: June 5, 2000

By Concurrent Resolution No. 74, the General Assembly has recognized June 6, 2000 as Transverse Myelitis Day in the State of Ohio. The Resolution was sponsored by Representative Ron Gerberry from the 65th House District. Richard J. Boyle, a member of The Transverse Myelitis Association, worked with Representative Gerberry on the development of the Resolution. Mr. Boyle, a resident of Youngstown, Ohio, contracted Transverse Myelitis in 1996.

The Resolution also recognizes Rachel Dorocak who celebrated her first birthday in March 2000. Rachel, a resident of Strongsville, Ohio, contracted TM when she was six months old and she remains paralyzed from the waist down. Her brothers, Matthew and Kevin, started the Reading for Rachel Program in order to raise funds for TM research.

TM is a devastating condition that effects persons in a variety of ways. It is a neurological syndrome caused by inflammation of the spinal cord and may occur in isolation or in the setting of another illness. Symptoms include back pain, numbness of the legs, headache, and rash. Typically, the outcome is eventual paralysis, sensory loss, and bowel and bladder dysfunction. Many individuals report experiencing chronic pain associated with their TM. The condition can occur to

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anyone of any age, and it can occur at any point along the spinal column. Historically, the scientific research and literature on TM has suggested that it was extremely rare with an annual incidence rate of approximately 1.34 per million population. However, more recent research and scientific literature indicates a more frequent rate of occurrence ranging from 3 to 4 per million population. There are approximately 34,000 persons with TM in the United States.

The Transverse Myelitis Association is a non-profit organization that offers support services and educational information to persons who have been diagnosed with TM. The TMA was started in 1994 by Deanne and Richard Gilmur in response to their daughter's TM diagnosis which occurred in 1990. She was eighteen months old at the time. The Gilmurs received little information about TM or support from the medical community at the time of her diagnosis. The ensuing years generally left them to search out their own answers to the many questions they had about treatment, recovery and support systems. Some of the best support they received was from the few families they were able to locate that had either a child or an adult with the TM diagnosis and had already experienced much of what they were just starting to go through. This led to the awareness and the determination that a method to provide the needed support and information for persons with TM and their families had to be initiated. The outcome was the TMA which has now developed into a registered non-profit organization with tax-exempt status under section 501 (c)(3) of the Internal Revenue Service tax code with over 2,200 members and a well organized and knowledgeable executive board. There are TMA members in all fifty states and from more than forty different countries around the world. There are approximately one hundred TMA members in the State of Ohio.

The TMA has grown steadily from the 180 members that existed in January of 1997. The Association has also continued to grow and develop in the way it provides vital and current information to the many individuals diagnosed with TM. The Association provides resources via printed materials, such as newsletters and brochures, and a Web site which was established in 1997. TMA also distributes articles describing the possible causes and treatments of transverse myelitis which were prepared for the Association by a Neurologist and Physiatriist who serve on the TMA Medical Advisory Board. TMA's outreach has also provided the medical community with a valuable resource for themselves and their patients as individuals diagnosed with TM are now regularly referred to TMA by members of the medical community.

The Association has heard from many members who have expressed their surprise, gratitude and joy in finding the TMA. Many persons with TM, as well as their

families, have found a source of support, information and knowledge through the organization. Instead of feeling alone with TM, many have discovered other individuals with TM residing near them through TMA's membership directory. The Association has brought people together from across the nation, as well as from around the world to share in the struggles and the hopes that ensue after a TM diagnosis.

TMA's relationships with the medical community have been instrumental in advancing the awareness of TM. Johns Hopkins Hospital has recently created the Transverse Myelopathy Center in Baltimore, Maryland which is the first clinic developed and dedicated to transverse myelitis treatment and research. (Contact Douglas Kerr, MD, Assistant Professor of Neurology, Co-Director, Transverse Myelopathy Center, (410)955-3730 or visit their Website at: www.med.jhu.edu/jhtmc). TMA has also developed strong ties with The Myelin Project located in Washington D.C. which is dedicated to promoting research and cures such as remyelination and nerve regeneration for demyelinating diseases. (Contact Augusto Odone, Founder and President, (202)452-8994 or visit their Website at: www.myelin.org).

For more information on The Transverse Myelitis Association, contact Sanford J. Siegel at (614)766-1806 or visit the TMA Website at: www.myelitis.org. Information on the TMA's Board of Directors, Medical Advisory Board, and the condition of transverse myelitis is available upon request.