



971-C S. Kenmore Drive  
 Evansville, IN 47714  
 Phone: 812-423-5943 Toll-Free: 1-866-514-4312  
 www.tristatems.org  
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**Offering support, care, and hope...*right here at home!***

**All Support Group Meetings and Newsletter Folding are Cancelled Until Further Notice!**

We are continuing to work behind the scenes to make sure the telephone calls, emails, and office needs are being handled. It is important to us that we provide up-to-date information on our website and Facebook page for you. Please stay safe, and stay well!

Send your email address to [officemanager@tristatems.org](mailto:officemanager@tristatems.org) to receive newsletters and programs!

**The Mission of the Tri-State Multiple Sclerosis Association is to enhance the quality of life for individuals living with MS & their families in Southern IN, Southern IL & Western KY**

**Updated list of Disease Modifying Therapies for Multiple Sclerosis**

The management of MS is a clinical success story. Until the mid-1990s, treatment for MS consisted of symptomatic control, usually a short course of high-dose steroids administered during exacerbations.

Since then, more than a dozen disease modifying therapies (DMTs) have been proven to slow the course of the disease.

FDA Indications for Currently Available DMTs <sup>12</sup>				
Agent	Approval	RRMS	PPMS	SPMS
Interferon b-1b (Betaseron; Extavia)	1993	✓		✓
Interferon b1-a (Avonex)	1996	✓		✓
Glatramer acetate (Copaxone/Glatopa)	1996/2018	✓		✓
Interferon b-1a (Rebif)	1996	✓		✓
Mitoxantrone (Novantrone)	2000	✓		✓
Natalizumab (Tysabri)	2004	✓		✓
Fingolimod (Gilenya)	2010	✓		✓
Teriflunomide (Aubagio)	2012	✓		
Dimethyl fumarate (Tecfidera)	2013	✓		✓
Alemtuzumab (Lemtrada)	2014	✓		
Peginterferon b-1a (Plegridy)	2014	✓		✓
Ocrelizumab (Ocrevus)	2017	✓	✓	✓
Siponimod (Mayzent)	2019	✓		✓
Cladribine (Mavenclad)	2019	✓		✓
Diroximel fumarate (Vumerity)	2019	✓		
Ozanimod (Zeposia)	2020	✓		
Monomethyl fumarate (Bafiertam)	2020	✓		

\* **August 2020- ofatumumab (Kesimpta) was approved by the FDA for treatment of relapsing and secondary progressive MS.**

\* **In March 2021- ponesimod (Ponvory) was approved by the FDA for treatment of relapsing MS and secondary progressive MS.**

FDA Approves Oral Ponvory™(Ponesimod) for Relapsing Forms of MS

March 19, 2021

UPDATED 3/30/21

The U.S. Food and Drug Administration has approved Ponvory™ (ponesimod, Janssen Pharmaceutical Companies of Johnson & Johnson) as an oral disease-modifying therapy for adults with relapsing forms of MS.

- Relapsing forms of MS includes people with [clinically isolated syndrome](#) (an initial episode of neurological symptoms), [relapsing-remitting MS](#), and active [secondary progressive MS](#). People with active secondary progressive MS have had progression of disability but still experience acute relapses and/or new MRI activity.
- Ponvory is similar to Gilenya® (fingolimod, Novartis International AG), Mayzent® (siponimod, Novartis International AG), and Zeposia® (ozanimod, Bristol Myers Squibb). Ponvory is thought to act by retaining certain white blood cells in the body's lymph nodes, keeping them out of circulation and from entering the central nervous system.
- In a 2-year, phase 3 clinical trial, Ponvory significantly reduced annual relapse rates and reduced MRI-detected disease activity compared with Aubagio® (Teriflunomide, Sanofi Genzyme). There was no significant difference in the proportion of people who experienced disease progression between those taking Ponvory or Aubagio.
- UPDATE: [A paper describing the clinical trial results](#) was published in **JAMA Neurology** online on March 29, 2021
- The most common adverse reactions reported from clinical trials were upper respiratory infection, increases in liver function tests, and high blood pressure. In addition, Ponvory may cause serious side effects (see below under **Potential Risks**).
- Starting Ponvory may result in temporary reductions in heart rate. To help reduce this potential side effect, Ponvory is taken in gradually larger doses over 14 days before the standard maintenance dose is achieved. There is no requirement for individuals to be monitored while taking the first dose, except for those with certain pre-existing heart conditions, who should be monitored for 4 hours when receiving their first dose.
- The company expects Ponvory to be available in April. Additional information on availability, cost, and patient support programs will be provided when they become available.

“MS is a complex disease, and any individual’s response to MS disease-modifying therapy can vary,” said Dr. Bruce Bebo, Executive Vice President of Research at the National MS Society. “It’s so important that people living with MS have access to effective treatment options. We are pleased that there is a new therapy approved for relapsing MS.”

**Note on starting a disease-modifying therapy during the COVID-19 pandemic:** Many experts believe it is safe to start a disease-modifying therapy during the COVID-19 pandemic. Therapies in the same category as Ponvory do not appear to increase the risk of more severe COVID-19 symptoms.

Taking a disease-modifying therapy is currently the best way to reduce MS disease activity and future deterioration. Selecting an MS therapy should be done by people with MS in collaboration with their MS healthcare provider, taking into account a variety of factors, including the effectiveness of any therapy they are currently taking, and weighing potential risks and benefits, costs, and lifestyle factors.

### Research on the horizon (From Medical News Today)

Some scientists are currently investigating the potential for stem cell therapy for MS. In a phase 1 study Trusted Source conducted at the Karolinska Institute, in Stockholm, Sweden, seven people with progressive MS received infusions of stem cells derived from each participant's own bone marrow. As early as 7 days after administration of the stem cell therapy, researchers found evidence of positive changes in the participants' immune systems. At 12 weeks, five out of six participants had no new characteristic lesions on follow-up MRI brain scans.

**As their understanding of the condition evolves, many scientists are investigating the root cause of MS.**

An analysis of the current data has revealed a possible connection between gut health and the condition. Data revealing relationships between the gut microbiota and the brain continually emerge and scientists are hopeful that diet modifications, probiotics, and certain drugs that balance the gut microbiome will play a role in MS treatment.

Also in development are remyelination and neuroprotection Trusted Source therapies.

Neuroprotection aims to protect the axons and myelin from further damage, while remyelination could restore lost function for people with MS.

Meanwhile, immunotherapy drugs would protect the nerves from destruction and rebuild neurons that have already sustained damage.

**Another potential treatment in phase 1 trials is a tumor necrosis factor-alpha (TNF-alpha) inhibitor called MYMD-1.**

TNF-alpha is a type of cytokine produced by white blood cells that regulates some aspects of the immune system. Overproduction of this cytokine is associated with several autoimmune conditions, including MS. MYMD-1 is a new type of TNF-alpha Trusted Source blocker that shows promise as a treatment for MS and other conditions.

Trials for therapies involving the gut microbiome Trusted Source, stem cells Trusted Source, neuroprotective treatments Trusted Source, remyelination Trusted Source, and MYMD-1 are still in the earliest stages. However, the possibilities provide hope that ongoing research will lead to effective ways to prevent MS and better methods of treatment.



Many people with multiple sclerosis are heat sensitive. MS research has proven that heat and humidity often aggravate common MS symptoms. MS research has also proven that cooling the body can help lessen the negative effects of heat and humidity on a person with MS.

The MSAA Cooling Program offers cooling vests and accessories for adults with multiple sclerosis as well as children diagnosed with pediatric MS. Cooling vests are commonly worn over clothing and contain insulated pockets that hold small ice packs. MSAA also offers smaller products to wear under clothing as well as accessories to help cool the neck, wrists and ankles. MSAA provides these products at no charge and items are shipped directly to the client. If you have any questions, please call MSAA at (800) 532-7667 or email [clientservices@mymsaa.org](mailto:clientservices@mymsaa.org).



More often than not, heat and MS don't mix. As body temperature rises, weakness, fatigue, visual disturbances, and other symptoms can become aggravated and temporarily worsen. While heat does not actually make MS worse, it does alter the passage of nerve impulses, causing a feeling of weakness, especially in the limbs.

But keeping cool can help you work, shop, and maintain your home during the summer months. It can also help you reclaim countless activities associated with the warmer seasons, like gardening, fishing, walking, biking, family outings, barbecues, and baseball games. Our Cooling Program offers a variety of items, free of charge, that will help you stay cool in the heat. Available items include: Cooling vests, Neck wraps, Wristbands, Hats

**The program cycle begins on February 1 and continues through June 1.**

**Program Services & MS Helpline [888-MSFOCUS \(673-6287\)](tel:888-MSFOCUS)**



We are excited to announce the Tri-State Multiple Sclerosis Association's Golf Scramble in memory of Ted Donosky is on! We would like to take this opportunity to ask for your support of our upcoming golf scramble. This annual event, which this year will be held in its entirety outdoors, will take place Monday, June 7, 2021 at the Rolling Hills Country Club in Newburgh, IN.

The sun is going to shine. We promise. So take the day off and enjoy a game of golf for a good cause. Gather your friends and put together a foursome for \$500.00. If you do not have a foursome, we will gladly team you up with other players. The individual fee is \$125.00. We will start the day with a great lunch, serve some cold beverages and lots of snacks along the course and wrap up the day with some great prizes. **A great day guaranteed!**

**Sponsorships available! Call 812-423-5943 for more information on how you can help!**