

You deserve a doctor or team of doctors who will be able to give a correct diagnosis and to treat all of your symptoms.

**FAQs:**

**Q.** How many people have Myositis?

**A.** Approximately 5 to 10 people per million receive a diagnosis of Myositis each year.

**Q.** Why aren't more doctors familiar with it?

**A.** There are more than 850,000 doctors in the US, yet fewer than 3,000 people in the US are diagnosed with all types of Myositis each year. It is easy to see why it is so difficult to find a doctor who recognized or is experienced in treating Myositis. You must be your own advocate!

**Suggestions for finding Myositis diagnosis and treatment:**

Email the Myositis Association and ask if they can recommend someone in your area. Information is provided to TMA by Myositis patients who are pleased with their health care providers.

([www.myositis.org](http://www.myositis.org), click Contact or email them directly at [tma@myositis.org](mailto:tma@myositis.org). While on TMA's website, find out if there is a support group (KIT Group) in your area by entering your zip code, and ask the members for recommendations. ([www.myositis.org/support-group-search](http://www.myositis.org/support-group-search)).

Post a request in the ***Myositis Support & Understanding*** group and any other online support groups to ask for recommendations.

Use the Muscular Dystrophy website to enter your zip code to find an MDA clinic. Myositis is a neuromuscular disease which falls under the Muscular Dystrophy Association. MDA clinics are located across the US and are typically operated by university hospitals and follow a multi-disciplinary approach. ([www.mda.org/locate](http://www.mda.org/locate)) (Canada: <http://muscle.ca/>). (England: <http://www.muscular-dystrophy.org/>) (Australia: <http://www.mda.org.au/>).

Johns Hopkins Medicine in Baltimore, Maryland, has the only Myositis Center in the world. While distance can be problematic, consider the experienced staff and state-of-the-art medical equipment. The doctors at the Myositis Center will work with your local health care providers for your future care, eliminating or minimizing future visits. ([www.hopkinsmyositis.org](http://www.hopkinsmyositis.org))

Stanford University Dermatology Department treats approximately 150 Dermatomyositis patients. Dr. Fiorentino is a former TMA Medical Advisory Board and Annual Patient Conference speaker.

There are about 18 doctors on TMA's Medical Advisory Board, some of whom see patients. A List of current members is posted under Myositis Support & Understanding Files section.

The National Institutes of Health (NIH) located in Bethesda, MD, encourages difficult to diagnose/treat patients to be seen at no charge. NIH is also conducts myositis studies. Dr. Mark Gouley is a TMA Medical Advisory Board member. (Email: [gourleym@mail.nih.gov](mailto:gourleym@mail.nih.gov))