



SUGGESTED MYOSITIS RESOURCES

Here are some suggested resources that we, MSU and its group administrators, feel may benefit you.

Our website, ***UnderstandingMyositis.org***, provides updated and reliable medical information and incorporates many things we have learned in the support groups. You can find information about symptoms, diagnostic protocols and treatments for the various types of Idiopathic Inflammatory Myopathies (Myositis), request and purchase Myositis-related products, read latest news and Myositis patient and caregiver stories, find clinical trials using our clinical trial matching tool, find Myositis programs and services, and find links to many other helpful resources. Visit www.understandingmyositis.org

The Myositis Support and Understanding Public Facebook Page is used to educate the public about Myositis and the many issues surrounding being a patient of or caregiver to someone with a disabling and often “invisible illness.” We encourage you and your family and friends to “Like” our page. This is a great tool to help those closest to you understand the many ways chronic disease impacts our lives. Visit www.facebook.com/understandingmyositis

Some ways to help you navigate our Facebook group and find valuable resources:

FILES

For a list of links and documents that we believe may help you along your journey with Myositis, click “Files” at the top of the group page. It is located under the banner and to the left of the search box.

SEARCH

You can search previous topics we have discussed by using the search box and entering a keyword or two. The search box isn’t always reliable and is very spelling- and case-specific, so if you don’t find what you are looking for try an alternative spelling or case. You may want to add multiple keywords, for example, instead of Prednisone; you may want to try “Prednisone dose” or “prednisone taper.”

LIVE, ONLINE VIDEO SUPPORT, EDUCATION, ACTIVITY SESSIONS

MSU is the very first myositis nonprofit to provide live online video sessions for myositis patients and caregivers. We host monthly video support sessions. Find upcoming sessions at <https://UnderstandingMyositis.org/events>

HELPFUL SUGGESTIONS:

The MSU website has some blog pieces which give tried-and-true suggestions that can be helpful in your journey. Here are a few that we recommend you read and start now.

We strongly urge you to keep a health journal. Here is a short piece from our site that explains the many benefits of keeping a health/medical journal:

Visit <https://understandingmyositis.org/benefits-keeping-journal-myositis/>

Do you have an Apple iPhone or iPod Touch?

Download the Smartphone App for Myositis

The App, currently in beta testing and only available for Apple products due to security, is provided in partnership with Portable Genomics, and allows patients and caregivers to track various health related data to take better control of your health. There are many other tools included as well. See full details and Download the App at

<https://understandingmyositis.org/app>

How do I explain myositis to others? Explaining myositis, the Idiopathic Inflammatory Myopathies, and how it affects our lives as patients is difficult. There isn't a simple, clear-cut answer for us. This article provides helpful ways to explain your disease.

Visit <https://understandingmyositis.org/explaining-myositis/>

SHARE YOUR STORY

We encourage you to share your story of living with Myositis or caring for someone living with Myositis. It can be about your journey, a specific topic, or even a video. We all learn from each other and sharing your story can also help others to understand what it's like to live with this rare disease.

Share your story here: <https://understandingmyositis.org/myositislife/>

“Share your Journey” session by Emily Filmore and Jerry Williams

At the 2015 TMA Annual Patient Conference Emily Filmore, Jerry Williams, and Dr. Pat Vitacco led a session titled “Sharing your Journey.” You can watch the session on our website to help you better understand why we suggest writing and keeping a journal. Visit:

<https://understandingmyositis.org/sharing-your-journey/>

Check out all of the latest myositis news at www.Understandingmyositis.org/news

SUPPORT FROM FAMILY AND FRIENDS:

We also have a closed Facebook support group for family and friends of those with Myositis, which is not open to patients other than some administrators who are patients and patient advocates. It's an opportunity for your friends and family to learn about Myositis as well as discuss how the disease impacts them. You can provide them with the link below so they can request to join. Myositis Family and Friends Support and Understanding: www.facebook.com/groups/myositisfamilyandfriends/

AWARENESS

Myositis wristbands and information cards are one of many ways we can help promote awareness and start meaningful conversations with others about Myositis, as they remind them we have a muscle disease or know someone who does. You can request free wristbands at

www.UnderstandingMyositis.org/shop and see how you can help raise awareness all year long at www.UnderstandingMyositis.org/awareness

WE ARE A PATIENT-CENTERED NONPROFIT: As an all-volunteer 501(c)(3) nonprofit, we rely on donations to develop programs and to give back to patients in need. You can make a tax-deductible donation on our website or by mailing a check. www.UnderstandingMyositis.org/donate

WANT TO GET INVOLVED?

You can join our team as a group administrator, volunteer, or join our board of directors if you feel you have the experience and energy to bring new ideas to MSU and you support our vision and mission.

STAY INFORMED

Follow Myositis Support and Understanding on our Social Media sites!

Facebook Page: <http://www.facebook.com/UnderstandingMyositis>

Twitter: <http://www.twitter.com/MyositisSupport>

Google Plus: <https://plus.google.com/+UnderstandingmyositisOrganization/posts>

LinkedIn Page: <https://www.linkedin.com/company/myositissupport/>

Pinterest: <http://www.pinterest.com/myositis/>

Instagram: <http://www.instagram.com/myositis/>

YouTube: <https://www.youtube.com/user/myositissupport/feed>

Register for your free membership with MSU at <https://UnderstandingMyositis.org/register>

