

Using the internet to find reliable information on Myositis diseases?

Think digital, get out of ***library mode*** and into ***internet mode***. The old way of finding information was to go to a library and try to find a book on the subject. Today you can search the whole library and virtually every other library in the world using a search engine like Google to get links in seconds. Type search term(s) like ***polymyositis and dysphagia, dermatomyositis and cancer, or Inclusion body myositis and treatment***. If you cannot find what you want on the first 2 pages of results, modify the search terms and try again, and again. One search term might turn up nothing but another might turn up a gold mine of hits. The more you search the more your preferred search engine will refine your search results and which sites you visit. Make sure you use the same engine on the same computer or network.

Professional articles are sometimes free and available in PDF format but many sites require registration, a subscription fee, or an individual payment for articles which can be quite expensive. TMA will often have important articles posted which can be accessed from the home page under "Explore Research."

Reliable sites (there are many others) to search:

The Myositis Association www.myositis.org

National Institutes of Health www.nih.gov

National Institute of Arthritis and Musculoskeletal and Skin Diseases
<http://www.niams.nih.gov/>

Johns Hopkins Myositis Center <http://www.hopkinsmyositis.org/>

Clinical trials, NIH <http://clinicaltrials.gov/>

JAMA Neurology <http://archneur.jamanetwork.com/journal.aspx>

Muscular Dystrophy Association <http://mdausa.org/>

Subscribe to free email services like ***MedlinePlus*** (NIH) or ***Science Daily*** to get daily emails in your areas of interest. Select your area(s) of interest and receive daily emails with the latest articles and links to additional information.

<http://www.nlm.nih.gov/medlineplus/listserv.html>

<http://www.sciencedaily.com/>

Search websites of ***Major Medical Institutions*** like Mayo Clinic, Northwestern Memorial Hospital, The Cleveland Clinic, to name a few.

Search reputable ***e-medical websites*** such as:

www.medicinenet.com

www.emedicine.com

Use TMA community forums. Post your questions to get answers from your peers. Many have the knowledge and experience you seek and cannot get from your doctor or from a website. However, remember that most posters are not medical professionals and there is good and bad as well as inappropriate (for your situation) information posted there.

Use Facebook groups or other social networking sites for myositis. There are many of them and some are open and some are closed groups. These can be the “wild west” of information but they can also be useful if you know how to use them.

Be skeptical of the following:

- Any site that is selling something
- Alternative medicine (diets, supplements, acupuncture) as primary treatments
- Anecdotal stories of success with no medical studies to back them up
- Doctors or others who claim to have a wonder treatment that the medical community ignores

Join a TMA KIT group if there is one in your community.

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