

Trials, treatments, and discussions



BYM 338 trial continues

TMA has been following the BYM338 trial for sporadic inclusion-body myositis and, after hearing from a few of the physicians conducting the trials that more spots had opened up in the U.S., sent out a notice to all IBM patients in the database. We encourage you to find a study center near you by going to www.clinicaltrials.gov; scrolling down toward the bottom of the page and clicking on the line "Show 43 Study Locations" for a drop-down menu of sites around the world.

The site unfortunately does not seem to be updated. Some of the sites that say "Not yet recruiting" are full; others may have been given some additional slots. Meanwhile, sites have been added around the world. Novartis asks that everyone call its main number, 1-888-669-6682, if they have questions.

Remember to also visit the Community Forum page where those interested can informally ask questions of those who have been in a drug trial. Go to www.myositis.org, click "community," then "Community Forum."



Stem Cell Therapy

TMA's Medical Advisory Board recently issued the following:

"Recent years have witnessed an explosion of stem cell 'therapy centers' that purport to cure diseases, including many forms of myositis. Lately, The Myositis Association (TMA) has received a number of inquiries regarding fat-derived stem cell treatments. These stem cell therapy centers promise to cure a myriad of diseases by using patients' own fat derived 'stem cells'."

TMA's Medical Advisory Board cautions against the use of such treatments, since there is very little scientific data to validate the claims that these stem cell treatments provide a viable treatment option or cure. Furthermore, there are risks associated with these treatments including potentially exacerbating the inflammation and thus worsening the underlying muscle disease, promoting tumor and cancer growth, and unnecessary risks to patients from the stress of surgery and anesthesia. The scientific evidence that these fat-derived stem cells stop the progression of myositis is non-existent, and favorable reports are based on purely anecdotal experiences, which have not been validated. If these treatments are to be tested,

they should be examined in a strictly research environment through a properly designed randomized clinical experimental trial.

Until there is scientific evidence supporting using fat-derived stem cells as a treatment for myositis, the potential risks outweigh the potential benefits."

Prednisone, rituximab, exercise

TMA presents quarterly online "live discussions" with international experts from TMA's Medical Advisory Board. During the summer series, we heard from medical advisors about new research regarding prednisone, rituximab and exercise.

If you are new to TMA, check our website for news of upcoming discussions. Have a previous engagement at the time of a discussion that interests you? No problem. Simply leave your question in advance and it will be answered in turn. Transcripts of sessions are posted shortly after each live discussion. Watch for news of the fall live discussion series. We also remind you via Facebook and Twitter. If you have a suggestion for a live discussion topic, email tma@myositis.org.

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