



Heartland

MYASTHENIA GRAVIS ASSOCIATION

MEETING DATES: THE SECOND SATURDAY OF THE MONTH

August 11, September 8, and October 13, 2018

At 10:00AM CST



The Heartland MGA group meets at 10:00AM the second Saturday of each month at Calvary Lutheran Church, **2941 N. 80th Street, Omaha NE 68134**. Calvary is located just north of Maple on 80th Street.

Saturday, July 14, 2018, the Heartland Myasthenia Gravis Association Support Group gathered at Calvary Lutheran Church. There were 10 in attendance.

Member, Keith Chambers, participating in RA Pharmaceutical's clinical trial 101495 brought us up to date on the study.

Keith advised there were some differences between the RA101495 clinical trial website and actual occurrence: The randomized test period is 13 weeks instead of 12. At the end of Phase I, Phase 2 begins with all the participants receiving the study drug. The study is scheduled to last 40 months from November 2017 or until FDA approved. Keith must confirm when injections are given in an Android phone.

Dianna distributed copies of the Quantitative Myasthenia Gravis (QMG) test discussed in the June support group meeting and available through MGFA. The test rates muscle weakness – mild, moderate, severe - of the eyes, facial muscles, arms, legs, and head as well as speech and swallowing and provides a total MG score. Randy opined the QMG would be a valuable tool for our doctors.

Randy noted our treasury funds, reported as \$648.25 in the July newsletter, were declining. Treasurer Madsen stated our expenses are approximately \$18.86/month (\$226/year) for postage to mail the newsletter and \$117.00 annually for website hosting fees. Occasionally, we purchase materials from the National foundation, brochures, videos, etc. to share with our members.

Because the support group has no membership dues, we rely on donations and fundraisers to refill the coffers. It has been several years since the group held a fundraiser which was the raffle of Nebraska football tickets. One of the suggestions was to contact the MDA and doctors for donations.

We are soliciting your input, Heartland MGA members. Do you have suggestions on how we can raise additional funds for our treasury? We would love to hear from you and will discuss your ideas at our next meeting.

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