



MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.®

Dear Friend:

The turn of the year has always been a time to reconnect and to revitalize, even as we reflect on accomplishments and progress towards our goals. In keeping with that tradition, we wanted to connect with you to tell you how your national organization, the Myasthenia Gravis Foundation of America (MGFA) is sharpening our focus on community service, volunteers and programs serving patients, cutting edge research, and our ultimate goal of finding a cure. 2015 was a year with significant progress to report.

- Through our nationwide information and referral service, Home Office has helped more than 1200 people living with MG to find the information and resources they needed to address the challenges of MG, and to move their lives forward.
- Provided news and information to the MG community through the *Foundation Focus* newsletter; the *Quarterly E-Updates* and periodic E-Blasts as well as the MGFA website, Facebook page and Twitter site.
- Created a new program for parents of children and teens with MG.
- Trained nine new support groups, providing orientation and training for new facilitators and updating our *Support Group Manual* and support group tools, enhancing resources for all of our group leaders.
- Offered educational webinars on topics such as: *The Role of Exercise in Taking Control of Your MG*, *Ocular MG* and *Understanding Myasthenia Gravis and Your Child*; (To watch, click on the link or go to:
<http://myasthenia.org/LivingwithMG/MGFAWebinarSeries.aspx>)
- Enhanced our app called **myMG** which people can use to keep track of their MG symptoms and fluctuations, and even generate reports for their physicians. (Get it through the Apple App Store or Google Play)

- Continued to grow **The MG Registry**, a research tool that will lead to greater understanding of MG long term. To become a part of this critical research project, click on the link or go to: <https://mgregistry.soph.uab.edu/MGRegistry/PortalLogin.aspx> and enter your information.
- Awarded \$350,000 in grants to fund critical research projects, including:

Transformative Research Program – This new MGFA research program funds innovative research projects with a high likelihood of producing fundamental change in our understanding of MG. The 2015 awardee will research the role of specific inflammatory cells in the manifestations of the disease. *Role of CD4 T cell subsets as drivers of MG diseases.*

MGFA—ABF Fellowship – along with the American Brain Foundation, MGFA is funding a project titled, *Clinical Significance and Pathogenic Mechanisms of LRP4 Antibodies in MG.* This exciting work is looking at a newly-discovered mechanism (i.e. a specific antibody) that causes MG for a subset of patients. This work should also provide insight into other subsets of MG.

MGFA Pilot Studies – 2015’s high impact projects are titled, *Novel cell specific therapy for autoimmune myasthenia* and, *Stem-cell treatment of congenital myasthenia associated with endplate acetylcholinesterase deficiency.* These cutting-edge projects are leveraging advances in cell therapy for MG and related disorders.

Consensus Conferences – MGFA has funded 2 conferences in the past year: *Development of Preclinical Guidelines for MG Therapeutic Development* and *International MG Treatment Guidelines.* These international conferences laid important foundations for improving research and MG patient care.

- Brought together nearly 200 patients, caregivers, nurses, doctors and exhibitors to share knowledge, experience and support at the 2015 MGFA National Conference, held in San Diego, CA.
- Expanded our major PR campaign, *June is MG Awareness Month* – with content in national and on-line newspapers such as The Los Angeles Times; San Francisco Gate; the Chicago Tribune and the Orlando Sentinel worth over a quarter million dollars in ad value. Activities took place around the country from television coverage in South Dakota to proclamations coast to coast, support group activities and increased website/social media activity.
- Provided extensive support for the #IhaveheardofMG Twitter Campaign originator, Florida MG patient and volunteer, Sandra Hardin.
- Connected nearly 400,000 new visitors from around the globe to life changing information and resources through MGFA’s website (www.myasthenia.org). More than 100,000 people visited the website anywhere from 2 to 200 times.
- Rallied the MG Community in 36 locations nationwide through MG Walks—creating awareness, building community and raising more than three quarters of a million dollars to support vital research and services. To find a walk near you, go to www.mgwalk.org

This past year, MGFA Home Office has enhanced its focus on community volunteers and programs with new staff, new volunteer committees, and renewed commitment to reaching individuals with MG wherever they are in the U.S. With our new volunteer and program directors we are aiming to galvanize volunteers in the field to create a much stronger program for the MG Community.

During 2016, MGFA aims to improve one to one support for patients, especially new patients through a new program MG Friends as well as increase the number of support groups; create new program initiatives aimed at expanding awareness of MG, advocating for patients and producing more learning resources and opportunities for patients and caregivers. To learn more about how you can be involved, click on the link or go to <http://myasthenia.org/HowcanIhelp/Volunteer.aspx> . To donate to MGFA, click on the link or go to <https://secure.acceptiva.com/?cst=04ca67> .

Thank you for all your support and involvement both nationally and locally.

Sincerely,

A handwritten signature in black ink, appearing to read 'Tor Holtan', written in a cursive style.

Tor Holtan
CEO