mg™ NEWS
MYASTHENIA GRAVIS FOUNDATION OF AMERICA
Support • Education • Awareness • Research

RESEARCH

MGFA Announces 2019 Pilot Grant Awards for 2020!

We are pleased to announce our pilot grant awards for the upcoming year. MGFA pilot grants recognize promising research in clinical and basic sciences for myasthenia gravis. Research grants are awarded based on our **Research Agenda**, which is focused around five priorities: biomarkers, diseases mechanisms, targeted therapies, patient outcomes and pediatric treatment.

To learn more about our research priorities and funding, see **here**.

- 2019 High Impact Pilot Project Grant Award: **Amanda C. Guidon, M.D**., Massachusetts General Hospital, Neuromuscular Diagnostic Center, *"Evaluation of automated techniques for decoding speech and movement abnormalities in myasthenia"* $55,000
- 2019 High Impact Pilot Project Grant Award: **Jeffrey T. Guptill, M.D.**, Duke University, *"Metabolic Pathways of Pathogenic Th17 Cells in Myasthenia Gravis"* $55,000
- 2019 High Impact Pilot Project Grant Award: **Ricardo A. Maselli, M.D**., University of California Davis, *"CSF Delivery of AAV9-mediated gene therapy of congenital myasthenic syndrome due to CHAT mutations"* $55,000

We wish to extend our congratulations to these recent grantees. With this promising work in the pipeline, coupled with the efforts of **MGNet**, the MG research landscape has never looked brighter!

To learn more about our research grants, see **here**.

MycarinGstudy Now Recruiting!

MycarinGstudy is a clinical research study developed with the myasthenia gravis (MG) community, and is evaluating a potential, first-of-its kind subcutaneous (under the skin) infusion treatment against placebo. The MycarinGstudy takes place in several different steps over an 18-week period.

To learn more about eligibility, inclusion and exclusion criteria, visit the announcement on our website **here**. Additional details are also available via the MycarinGstudy website **here**.

Strengthen MG Research By Joining the MG Patient Registry Today!

As the MGFA community continues to grow, we ask each and every one of you that resides in the U.S., 18 years of age or older, to think about joining the MG

Patient Registry. The registry has already made a huge difference for so many people with MG. The information you provide allows researchers to start and continue clinical trials, which leads to increased treatment options. The MG Patient Registry is an active database of individuals with myasthenia gravis (MG), developed for the purposes of research, treatment, and patient information. The registry is free to join and all data is protected by federal privacy laws.

More than 3,000 patients strong, the MG Patient Registry is the largest database to help propel research for MG. We ask you to help strengthen research and understanding about MG by joining now.

Join the MG Registry here

AWARENESS & ALERTS

Join the Momentum of the MG Walk!

The MG Walk is dedicated to creating awareness, renewing hope, and generating a vast network of community and support, all while raising important funds for MGFA. The MG Walk puts the power directly into the hands of MG patients and allows everyone battling this illness to become the driving force behind funding for MG research, and ultimately, a cure.

Please see a list of upcoming MG Walks below. New MG Walks launch daily, so make sure to stay tuned via **MGWalk.org**!

- February 8, 2020: Coconut Creek, FL
- February 22, 2020: St. Petersburg, FL
- February 29, 2020: Tallahassee, FL
- March 14, 2020: Atlanta, GA
- April 4, 2020: Fort Worth, TX - **National MG Walk**

If you are interested in volunteering for an MG Walk, please see **here**.

MGFA Brochures: Disponible en Español!

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La misión de la MGFA es facilitar a los pacientes un diagnóstico oportuno y cuido óptimo de la miastenia gravis y los trastornos directamente relacionados con ella, así como mejorar su calidad de vida a través de programas de servicios al paciente, información pública, investigación médica, educación a los profesionales, apoyo de sus intereses y cuidados al paciente.

El propósito de esta publicación es proporcionar al lector información general para fines exclusivamente educativos. Como tal, no aborda las necesidades individuales de los pacientes y no debe ser utilizada como fundamento para tomar decisiones sobre el diagnóstico, atención o tratamiento de enfermedad alguna. En contraste, estas decisiones deben basarse en las recomendaciones de un médico o profesional de la salud que conozca personalmente al paciente. La información que contiene esta publicación refleja los puntos de vista de los autores, pero no necesariamente los de la Fundación Americana de la Miastenia Gravis (MGFA). Cualquier referencia a un producto, proveedor o uso específico no representa nuestra aprobación del mismo. La MGFA, sus promotores, empleados, directores, su Junta de Consejo Médica/Científica, su Junta de Consejo de Enfermería o sus miembros, se abstienen de garantizar la información que contiene esta publicación. Específicamente desconocen cualquier garantía de comerciabilidad, idoneidad para cualquier propósito particular o confiabilidad de la información contenida en este documento, y no asumen responsabilidad alguna por cualquier daño u obligación que resulte de utilizar dicha información.

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TRATAMIENTO DE EMERGENCIA DE LA MIASTENIA GRAVIS

Información y orientación para personas con MG, sus familias y los profesionales que les atienden

Select MGFA brochures are now available for download in Spanish! Printed versions will be available soon. We produce and distribute informational pamphlets and handouts for the general public. These materials provide information on myasthenia gravis, medications, treatments, MG management, as well as information on our services.

To see available brochures, visit our website **here**.

Make a Special Gift this Holiday Season!

Still looking for the perfect gift for someone special on your holiday list? Imagine the delight of receiving a personalized snowflake certificate acknowledging your gift to MGFA in their honor. Like snowflakes, all cases of MG are unique.

Your thoughtful gift brings us closer to a world without MG! Please donate today by clicking **here**.

COMMUNITY & PROGRAMMING

Know Your Antibodies Webinar Now Available!

While our MG Patient Registry is 3,000 patients strong, the majority of patients do not know their clinical markers for MG. On December 5, Dr. Pushpa Narayanaswami discussed an overview of immunology, the symptoms and functional changes that come with MG, the different types of antibodies in MG and follow-up testing for those antibodies.

Interested in learning more? Click **here** to view the webinar.

Save the Dates!
2020 National Conference
April 5 – 7, 2020

The National Conference is the largest gathering of the myasthenia gravis (MG) community in the U.S. We welcomed more than 300+ attendees to our conference in Atlanta in 2019. Let's make 2020 in Texas even bigger and better! Presentations and breakout sessions cover all aspects of MG, from medical to personal to social. MG experts, MG community leaders, people with MG and family members come together to share their experience. Join us to gain knowledge, share resources and speak with others "who understand!"

When: April 5-7, 2020 | Where: **Omni Fort Worth**

What's Coming in 2020?
- Complementary Medicine: Therapies & Strategies to Help Better Manage MG
- Confident Caregiving: Strategies That Can Help You Along the Way
- MG in the Autoimmune Disease Space: What Can We Learn & Its Impact on Treatment
- MG & Drug Interactions

Stay tuned via **myasthenia.org** and social media for more details!