



## RESEARCH

### **Descartes-08 CAR-T Cells in Generalized Myasthenia Gravis Research Study**

Cartesian Therapeutics, Inc. is sponsoring a new study to evaluate the safety and preliminary efficacy of Descartes-08 CAR T-cells in patients with Generalized Myasthenia Gravis. The participating locations include the University of Miami and University of California – Irvine. To learn more about eligibility, inclusion and exclusion criteria, visit the announcement on our website [here](#).

Additional information is also available via the National Institutes of Health Clinical Trials database [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!**



We are 3,000 patients strong, but we could still use your help!

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.

**[Join the MG Registry here](#)**

## ADVOCACY

### Rare Disease Week Stipends Available- Application Closes on 12/2!



The EveryLife Foundation will offer a limited number of travel stipends to help more advocates to attend Rare Disease Week on Capitol Hill, which will take place from February 25-28<sup>th</sup> in Washington, DC. Please find the application [here](#). The deadline for applications is **December 2, 2019**. For more information on the week of events, please click [here](#).

### Medical Nutrition Equity Act: Add Your Voice for MG!

The Medical Nutrition Equity Act (MNEA) has been introduced into the House of Representatives as [HR2501](#). This legislation provides insurance coverage for medically necessary foods and formulas, like thickening agents for swallowing issues. [Patients & Providers for Medical Nutrition Equity](#) would like to hear from other disease groups and advocates like you.



To learn more or to share your story on how this bill could impact you, click [here](#).

## AWARENESS & ALERTS

### Medical Device Cybersecurity: What You Need to Know



As technology evolves, many medical devices are becoming more advanced and contain software that can connect to the internet or other devices. Although the U.S. Food and Drug Administration (FDA) regulates such devices and works to secure the integrity of their purpose from cyber threats, patients and caregivers can also play a role in protecting themselves.

To read more and learn some tips on how to keep your information safe, click [here](#).

### 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](https://mgwalk.org)!

- December 7, 2019: Scottsdale, AZ
- 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

If you are interested in volunteering for an MG Walk, please click [here](#).

## **America Recycles: Bottles, Cans, Newspapers ... and Wheelchairs?**

The Assistive Technology Act Programs funded by the Administration for Community Living (ACL) are reusing, refurbishing, and recycling donated assistive touch and durable medical equipment with the purpose of providing them to those who cannot afford the cost of the devices otherwise.



To read more about the different programs offered by state and eligibility requirements click [here](#).

## **Workplace Giving: One of the Many Ways You Can Support MGFA!**



Your fundraising changes the world for people affected by MG. Your help drives research in understanding the cause, development of treatments, and eventually, a cure for MG. Your fundraising supports our daily work in connecting, supporting, educating and providing



resources to people with MG. One of the easiest ways to support that work and our mission is through workplace giving.

Through the [Combined Federal Campaign](#), federal government employees and members of the U.S. Military Forces can support the MGFA by designating their contribution to (CFC) #11240. To learn more about workplace giving options to support MGFA, click [here](#).

## COMMUNITY & PROGRAMMING

### **Know Your Antibodies Webinar**

Presented by Pushpa Narayanaswami, MD  
December 5, 2019 at 8pm EST

While our MG Patient Registry is 3,000 patients strong, the majority of patients do not know their clinical markers for MG. This webinar will provide you with 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.

This webinar will help to answer the following questions:

- What are antibodies?
- What is an immune response?
- What is autoimmunity?
- How does MG fit into the larger autoimmune disease space?
- What are antibodies in MG and how are they tested for?



We hope this webinar will help you better navigate your health with MG through education around antibodies. To register, please click [here](#).

## MakinG Connections Educational Programs provided by Alexion



Alexion gMG events are held all across the country and online. Listen to a physician speak about generalized myasthenia gravis management, hear a patient or caregiver share their story about living with gMG, and learn more about caring for someone with gMG. To find a gMG event from Alexion in your area, click [here](#).



This #GivingTuesday, we ask you to join the fight against MG by supporting programs and research to help those affected. Make sure to check out our social channels to see how you can be a part of our 'Blizzard of Support' campaign!