



## **FOR IMMEDIATE RELEASE**

### **Myasthenia Gravis Foundation of America (MGFA) Re-launches the MGFA Global MG Patient Registry with Partner Alira Health**

*Patients living with myasthenia gravis (MG) provide their health and symptom experience data in a safe, secure registry to drive new research and discoveries for improved disease understanding, better patient outcomes and treatments.*

**BOSTON, MA – January 25, 2023** – The [Myasthenia Gravis Foundation of America \(MGFA™\)](#), the largest, leading patient advocacy organization solely dedicated to finding a cure for the rare neuromuscular disease myasthenia gravis (MG) while improving the lives of those living with MG, re-launched its [MGFA Global MG Patient Registry](#). The registry enables patients diagnosed with MG to securely, safely submit their health and symptom data that will help researchers design and drive new research studies and clinical trials to improve disease understanding and patient outcomes and find better treatments for MG.

The MGFA has partnered with [Alira Health](#), a global healthcare firm whose mission is to humanize healthcare in partnership with patients, to develop and manage the registry while providing data analysis reporting. Alira Health has provided new, more efficient methods for patients to submit their data via a mobile phone application called Health Storylines™. The re-launch of the registry capitalizes on technological advances and better understanding of MG. Patients will add their data to the structured registry questionnaire twice a year, while also having the opportunity to contribute their day-to-day health experience data using the app, so that researchers can benefit from a deeper understanding of the lived experience of patients with MG.

“It is critical for researchers and clinicians to have access to real, up-to-date patient data to help design and build research studies and trials to more accurately prove out hypotheses and objectives,” said Samantha Masterson, president and chief executive officer of the MGFA. “Patients from around the world require data privacy, and now they can safely and securely share their data to help research sponsors make MG discoveries that could lead to better outcomes and treatments. Patient contributions to the registry will help drive new and better ways to treat MG.”

“We see a future where patients are empowered to carry their own end-to-end health care information to obtain more effective treatments, better manage a disease, be healthier, or actively equip their circle of care to assist them,” said Gabriele Brambilla, chief executive officer of Alira Health. “MGFA Global MG Patient Registry is an important step on this path. We are honored to partner with them to help improve the lives of patients with myasthenia gravis.”

This patient registry is a longitudinal, global, online repository of MG patient symptom and health data, shared directly by MG patients via online and mobile tools. It is safe, secure, and HIPPA-compliant, ensuring that patient data is protected and anonymized, so no one can directly attribute specific data points to members. The data is managed and maintained by the MGFA and its partner Alira Health to ensure data accuracy, hygiene, and quality.

Finding and enrolling sufficient numbers of patients in a short amount of time is a key challenge for research sponsors, especially in a rare disease space with a diverse set of manifestations. The registry data can supplement the trials so

research professionals can move forward. Researchers, clinicians, and scientists will collaborate and invest with the MGFA to receive aggregated, anonymized yet detailed data reports that they can utilize to design studies, research scenarios, and run trials and research studies to help make new discoveries and test potential treatment pathways.

These research sponsors will be able to leverage longitudinal MG patient data to augment their trials and research studies, while testing new hypotheses and/or capturing long-term follow-up outcomes. Since the data is anonymized and aggregated, researchers will not have to solely rely on actual clinical trial applicants in order to run their research studies – enabling them to obtain final outcomes and results that could identify new treatments faster.

Data reporting will be communicated to the patient registry members so patients can see, in aggregate, the types of outcomes from the patient population. All published research will be communicated to the MG Community so they can read how the registry helps drive new discoveries.

MG patients can join the registry by using the following link to access and establish an account page.

<https://www.mgregistry.org/>

### **About Alira Health**

Alira Health is an international patient-centric and technology-enabled advisory firm whose mission is to humanize healthcare. We work with healthcare and life sciences organizations looking for support across their entire solutions lifecycle. From development to medical care, we complement our clients' expertise with a full spectrum of services including research and clinical development solutions, technology-powered consulting, and real-world evidence. Alira Health's integrated and multidisciplinary team of over 600 scientists, strategists, economists, clinicians, and biostatisticians collaborate across our North American, European, and Asian offices and advise 80% of the top 50% of MedTech companies and 75% of the top 50% of Pharma companies.

### **About MGFA**

The Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding a cure and improved treatments for the rare neuromuscular disease myasthenia gravis (MG) by funding critical research discoveries and providing patient-centric programs, guidance, events, and webinars to connect, educate, and assist members of the global MG Community. You can visit the MGFA at [myasthenia.org](http://myasthenia.org).

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