MG Patient Registry

The only way we can really understand MG is if we have more information about who gets MG, when they get it, their symptoms …

Robert Ruff, MD, PhD

Many rare disease registries exist now and have helped identify costs of care and patient challenges that could not be identified in any other way.

— Henry Kaminski, MD

I joined the MG Patient Registry because it was a chance to have my voice heard. It was also one way I felt I could help my fellow MG Patients out there hoping for better treatments or perhaps one day a cure.

— Roger

I felt empowered after I completed the MG patient registry. These were my answers, my story…Not told by anybody else. Not how anyone else views my life since I’ve had MG; but how I view my life since diagnosis.

— Celia

OUR MISSION

The mission of the Myasthenia Gravis Foundation of America, Inc. is to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy and patient care.

You can find more about MGFA's resources for patients, caregivers and healthcare providers by visiting www.myasthenia.org or learn more and share by visiting MGFA on Facebook.

The Myasthenia Gravis Foundation of America, Inc. is a Community Health Charities Member Agency. Select MGFA by choosing the Community Health Charity Combined Fundraising Campaign number 11240.

This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs, and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition.

Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient. The information contained in this publication reflects the views of the authors, but not necessarily those of the Myasthenia Gravis Foundation of America (MGFA). Any reference to a particular product, source, or use does not constitute an endorsement. MGFA, its agents, employees, directors, volunteers, its Medical/Scientific Advisory Board, and its Nurses Advisory Board or their members make no warranty concerning the information contained in this publication. They specifically disclaim any warranty of merchantability, fitness for any particular purpose, or reliability regarding the information contained herein, and assume no responsibility for any damage or liability resulting from the use of such information.

Myasthenia Gravis Foundation of America, Inc.
355 Lexington Ave., 15th Floor, New York, NY 10017-6603
(800) 541-5454 | (212) 297-2156 | (212) 297-2158 fax
mgfo@myasthenia.org | www.myasthenia.org

©2017 by Myasthenia Gravis Foundation of America, Inc.
Why a patient registry? The MGFA launched the **MG Patient Registry** to help expand our knowledge about MG and move us closer to improved treatments and a cure. Through the Registry the MG Community will help identify how each of us was diagnosed, how we are being treated, our insurance challenges, and how we are feeling.

By making a patient community more accessible and understandable, a patient registry and its bounty of information can encourage pharmaceutical developers to pursue drug discovery in a disease.

Myasthenia gravis is a rare disease and every patient is like a “snowflake,” someone with a unique experience of MG. So having a significant number of registry participants is essential to getting a full picture of the MG community and what patients face.

**Privacy.** Every patient can still be assured of complete confidentiality. For more see the Privacy & Security Statement at right.

The ultimate success of the **MG Patient Registry** depends on the participation of people like you. Without your participation we can’t succeed, but working together we can make a difference.

If you are an adult1 with MG who has not yet signed up and completed the **MG Patient Registry** Survey, please do so, and be part of the team helping to overcome MG. Once you have completed the initial questionnaire, you’ll receive a follow-up survey every 6 months helping to build the body of knowledge about MG.

---

**MG Privacy & Security Statement**

The MGFA, MGFA Patient Registry Committee, and the University of Alabama at Birmingham's Institutional Review Board for Research all provide oversight for operation of the MG Patient Registry. These work in parallel to ensure that the purposes and objectives of the registry are supported and to ensure that the rights and welfare of those enrolled in the registry are protected. For a full text of the Privacy & Security Statement visit the Registry Website at [http://www.mgregistry.org](http://www.mgregistry.org) and choose the Become a Participant tab.

---

**How to join.** To begin, you will sign a consent form and register on-line to participate. Once registered, you can print out a copy of the Registry Forms, review them, and then pull together your information. Plan to gather your patient records – medications, procedures, test results. You may need to check in with your neurologist to fill in some data. You can save your work and return to it at your convenience. For more information go to [http://www.mgregistry.org](http://www.mgregistry.org/) and choose the FAQ, frequently asked questions tab to learn more.

The success of the **MG Patient Registry** depends on you as a team member, whether you are a patient who can sign up (and encourage others to sign up) or an MG support group leader or physician who can encourage participation. Thank you for considering the Registry!

---

1 Eighteen years or older.

*Note: Development of a pediatric registry is in progress.*

---

**Vision of the MG Patient Registry**

The vision of the MG Patient Registry is to support MGFA’s vision of “a world without MG,” while aiding in the improvement of care and quality of life for persons with myasthenia gravis and their families. The MG Patient Registry is designed to:

- Offer a confidential means for patients to provide information that will be useful to medical/research communities in assessment of disease course, use of various therapies, and estimation of disease costs.
- Provide a system for investigators to gauge the potential for trial recruitment and to communicate with patients directly about potential research investigations, while respecting their privacy.
- Educate patients, caregivers, non-expert health care providers, and funding entities about MG through the use of various media. For example, a newsletter with articles about research findings and other topics relevant to individuals with MG will be sent to participants annually.

---

**To register go to:** [https://mgregistry.soph.uab.edu/MGRegistry/PortalLogin.aspx](https://mgregistry.soph.uab.edu/MGRegistry/PortalLogin.aspx)

Or, visit the MGFA website and click on the banner when it cycles to the Registry promotion to get to the sign-up page. If you need help, please contact the MG Patient Registry — Email: MGR@MGregistry.org, or Phone: (855) 337-8633 toll free.