

The logo features the letters 'MG' in a bold, blue, sans-serif font. A green swoosh curves around the 'G', and a blue swoosh curves around the 'M'. Below the 'MG' is a grey swoosh that extends to the right, underlining the text.

MG Patient Registry

The Myasthenia Gravis Patient Registry is a project of the Myasthenia Gravis Foundation of America (MGFA), executed by the Coordinating Center at the University of Alabama at Birmingham (UAB) and the MGFA Registry Committee. The purpose of the Registry is to develop and maintain a current database of persons with Myasthenia Gravis (MG). The database will include **identifiable** information that you voluntarily provide about your demographics, medical history, family history, lifestyle, and quality of life along with updates of your medical condition every 6 months. Additionally, the database will be used to provide **de-identified** data to investigators for research purposes and to notify patients of opportunities to participate in current and future research. These efforts may lead to a better understanding of MG and improved therapy.

Please read the following informative statements before signing up to participate in the MG Patient Registry:

- You have to be at least **18 years** old to participate.
- All information you provide will be used for research purposes only, and your responses will be kept private and confidential.
- Your personal contact information will be kept strictly confidential and will not be released without your written consent. Your personal contact information will never be sold for advertising or fundraising.
- The information you provide will be used for scientific research. Data will be released only to approved researchers, and all identifiable information will be removed prior to releasing your information to any researcher. Data you provide may be used in scientific publications; however, your identity will not be given out.
- By being enrolled in the Registry, you may agree to be notified of research studies for which you may be eligible; however, you are not obligated to participate in these additional studies.
- Participation in the Registry is your choice and completely voluntary. It will take approximately 1 hour to complete the initial questionnaire. You will receive additional questionnaires every 6 months in order to update your contact and health information.
- There will be no cost to you for taking part in this study, nor is there any penalty if you decide not to participate. You are free to withdraw from this research study at any time by calling the toll-free number 1-855-337-8633.
- The MG Registry newsletter will be sent to participants once a year either by mail or email. This publication will include topics relevant to individuals with MG (e.g., research findings, news or information regarding therapies, on-going research, etc.). There is no cost to participants for this publication.
- This study is expected to continue indefinitely. There is no specified termination date.
- You will not benefit directly from taking part in this study. However, this study may help us better understand how to treat Myasthenia Gravis in the future.

- Risks associated with this study include possible loss of confidentiality, as well as potentially being inconvenienced and stressed due to completion of questionnaires every 6 months.
- The MGFA will own all of the data you provide, but will not have access to individual level data.
- If you have questions, concerns, or complaints about the research, you may contact the Principal Investigator, Gary Cutter, PhD at (205) 934-4340. If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the Institutional Review Board for Human Use (OIRB) at (205) 934-3789 or 1-855-860-3789. Regular hours for the OIRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday.
- Please print a copy of this page for your records.