

VALUE-MG Study

Participant Information Brochure

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This study aims to determine the best times to use intravenous immunoglobulin (IVIg) to improve functionality in individuals with MG compared to other treatments. The findings will guide the creation of more effective treatment plans to enhance the overall well-being of individuals with MG. If you choose to participate, we'll gather extra health information from you, but your MG treatment will stay the same.

The purpose of the project

IVIg therapy has been proven to enhance how well individuals with MG feel, but we need more information to know when, how often, and how much should be used for the best results. Our goal is to determine the ideal way to use IVIg to make people with MG healthier and happier. For instance, does starting IVIg early or using it more often make a difference? The details we collect in this study will help doctors and people with MG decide on better treatment plans in the future. To do this, we need information directly from individuals with MG and their medical records. This data is crucial for justifying government support for the most effective treatments for people with MG and encouraging further research into new treatment choices.

Your participation is very important

Your participation is really important because when more people join in, our research findings become more robust and dependable. This helps doctors and patients, ultimately improving outcomes for those with MG. It's essential to note that while the research itself may not directly benefit any individual patient, your involvement contributes to advancing overall understanding and care for everyone with MG.

What does participation involve?

If you decide to take part, we'll ask you to sign a consent form. It's important to know that your MG treatment won't be affected. Every three months, we'll invite you to fill out some questionnaires about your symptoms over three years.

What will happen to your information?

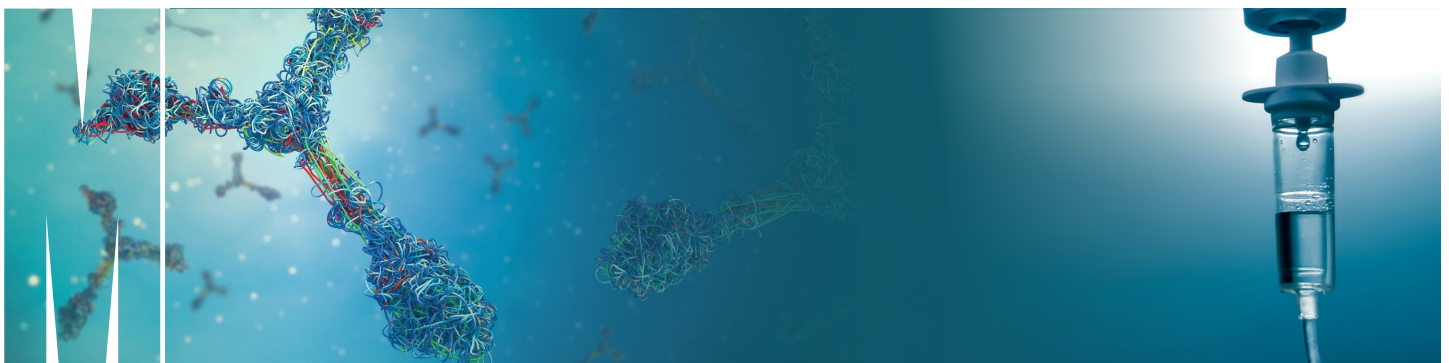
Your information will only be used for research related to this project. We'll keep the data on secure servers at Monash University, and it will be deleted seven years after the final results are published to ensure enough time to validate the research findings.

How is the research project being conducted?

We'll gather information from MGBase, patient surveys, and records from hospitals and the government. Your data will be kept private and made anonymous.

Who is organising and funding the research?

Professor Dennis Petrie from Monash University leads this research, funded by the Medical Research Future Fund (MRF) Grant.



If you are interested in participating in the study, have any questions or require more information, please contact us via email.

Email: value.mg@monash.edu