What does it really mean to Participate in Progress?

We answer some of the most common questions below.

Do I need to be invited to join a clinical trial?

One way to join a clinical trial is to be invited. If a doctor thinks you may meet the criteria to participate in the study, then they may tell you about the trial to see if you want to learn more about the trial and what is involved with participating.

However, you do not need to wait to be invited! If you learn about a clinical trial that is of interest to you, the first step would be to discuss it with your regular neurologist, who knows you the best. Your doctor can find out if you are eligible to join the trial. If you are, then your doctor should be able to get you in touch with the people who are running the trial.

You can also contact the company who is responsible for a trial (study sponsor) that you are interested in learning more about. The company can help get you in touch with a clinical trial location nearest to you to discuss more details.

What are some important things to ask my doctor or a study doctor about participating in a clinical trial?

Here are some questions you may want to ask.

- What is required for me to participate?
- What are the risks and benefits?
- Are there any costs to me? If I must travel, who will cover the expenses?
- What is already known about the investigational medication being studied? Has it been given to anyone before?

What are the risks of participating in a clinical trial?

Any potential known or unknown risks will be discussed with you at the very beginning of the process. This step is called Informed Consent. The informed consent process is a discussion intended to ensure the researchers (clinical trial staff) share all that they know about the clinical trial including its risks, and allow you to ask questions. If you are not satisfied with the answers to your questions, are not comfortable with any risks you learn about, or if there is too much uncertainty, then you can choose not to participate. It's always up to you.

What benefit do I get from participating in research?

You may experience certain benefits from participating in clinical research, depending on the type of study. Benefits may include the following:

- Help others who have MG now and in the future by participating in the study of new medicines
- Experience more frequent interactions with healthcare providers who are experts in MG

The specific benefits you may experience will be unique to the trial you join and can be discussed with the clinical trial team running the study.

Who will cover the costs for me to be in a trial?

Typically, you would not be responsible for the costs to be in a trial. The medical care that is needed as part of the trial is covered for you. You may be reimbursed for travel or other expenses related to participating in the trial. These details will be discussed during the informed consent process with the clinical trial team.

Can I change my mind even after I start in a clinical trial?

Yes. Even after you consent (give your permission) to participate in a clinical trial, you are free to change your mind at any time. You should feel free to speak up if you no longer want to participate.

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