Do you have Primary Progressive Multiple Sclerosis?

If so, you may qualify for an NIH research study.

The Neuroimmunology Branch (NIB) of the National Institutes of Health is conducting a study to investigate the efficacy of an oral experimental drug in primary progressive multiple sclerosis. The study will be conducted at the NIH Clinical Center in Bethesda, Maryland, on an outpatient basis.

We are seeking participants:

- ages between 18-55
- diagnosis of Primary Progressive Multiple Sclerosis
- not taking any immunomodulatory drugs

The study involves a one year baseline after which participants will receive the medication or placebo for 2 years. Medical evaluations, MRIs, and blood work will be performed at scheduled intervals during the 3-year study. The visits will last 2-5 hours each and will be every month the first 3 months and then every 6 months for the remainder of the study.
There is no cost for participation.
Travel reimbursement will be provided.

Please call 301-496-0064 for more information about participating in this study.

Do you have Primary Progressive Multiple Sclerosis?

Researchers at the NIB are seeking adults ages 18-55 with a diagnosis of Primary Progressive Multiple Sclerosis to participate in a randomized, placebo controlled, double blind study investigating the efficacy of Idebenone in this disease. Participation will include medical evaluations, MRI, bloodwork, and lumbar puncture performed at the NIH Clinical Center on an outpatient basis.

Q. What's involved in the study?

A. This study is a randomized, placebo controlled, double blind study. Individuals who qualify and decide to participate will be randomly assigned to receive the study drug or a placebo. Neither the individual nor the investigators will know which patients are taking the study drug, until the conclusion of the trial. All individuals participating in the trial will be monitored at scheduled intervals, and at the conclusion of the trial, based on clinical and MRI assessments, it will be determined if the study drug is effective in this disease.

Q. How will I benefit?

A. If this drug proves to be effective, the progression of your disease may slow down or even improve.

National Institutes of Health

National Institute of Neurological Disorders and Stroke

Q. Are there risks involved?

A. Over 8 million individuals have been treated with Idebenone for other neurological conditions, including Alzheimer's disease. Idebenone has been found to be well tolerated and safe. The most common side effects reported have been gastrointestinal symptoms, including nausea, diarrhea and loss of appetite.

Q. Will this cost me any money?

A. No, you will not be charged for any part of the study.

Q. How much time does the study take?

A. The study will last 3 years. During the initial screening period, you will need to be seen several times over approximately a 3 month period. After that, you will need to return approximately every 6 months. Over the 3 years, you will have a total of approximately 15 visits. Visits may vary in length, but are usually from two to five hours long. We will try to schedule visits at times that are most convenient for you.

Q. How will my primary neurologist be involved?

A. You will remain in the care of a non-NIH neurologist who will manage any symptoms and guide treatment decisions that are unrelated to the clinical trial. NIH may make recommendations for your care, but will not act as your primary neurologists. All management related to the clinical trial, such as MRIs and bloodwork, will be performed at the NIH.