



# **RESEARCH REGISTRY**

#### WHO WE ARE

Moss Rehabilitation Research Institute (MRRI) was established in 1992 to lead and coordinate research at MossRehab. Our researchers are at the top of their fields in trying to improve the lives of people with neurological disabilities. In 2000, MRRI established the MRRI Research Registry, a computer database, to provide a way for people to learn about these research opportunities that may benefit them or others.



### WHAT WE DO

The MRRI Research Registry allows researchers to identify individuals who are interested in volunteering for ongoing or future research studies. Participants in the Research Registry include people with a diagnosis of stroke, traumatic brain injury, Parkinson's Disease or Parkinson-like symptoms, as well neurologically healthy individuals such as the family and friends of Registry participants and other interested members of the community.

#### WHO WE PROTECT

If you join the Registry, a record for you will be created in our database and will include the best ways to contact you, and information about you that is used to match you to studies at MRRI. All information in the Registry is kept confidential following federal Health Insurance Portability and Accountability Act (HIPAA) guidelines. Research projects that recruit participants from the Research Registry are conducted with Institutional Review Board oversight to maintain the highest standard of research ethics. We may reach out to you, or you can reach out to us, about being a part of the Registry.

Research Registry Office 215-663-7147 <u>MRRIregistry@jefferson.edu</u>



50 Township Line Road Elkins Park, PA 19027

https://mrri.org/patient-research-registry/



## FREQUENTLY ASKED QUESTIONS

#### What are research studies like at MRRI?

MRRI research is devoted to improving the lives of individuals with neurological disabilities.

Researchers study problems with speech and language, attention, memory, movement, and emotional well-being and which treatments work best.

#### Who can participate in the MRRI Research Registry?

The Research Registry includes people with a diagnosis of stroke, traumatic brain injury, and Parkinson's Disease or Parkinson-like symptoms. Neurologically healthy individuals such as family, friends, and other interested members of the community can also participate.

#### Why should I join the MRRI Research Registry?

Participating is voluntary and will give you the opportunity to learn about research studies that may interest you.

You may help improve rehabilitation services for people with neurological disabilities.

You might volunteer for a study using a new therapy that could help a problem you or a loved one may have.

You are not obligated to participate in any particular study and can say no at any time.

#### I am interested. What happens after I join the Research Registry?

If you match the goals of a MRRI-sponsored study, you will be contacted by a research team member.

You decide if you want to learn more about the study, and if you want to participate in the study.

If you are interested and eligible to participate in a study, you will participate in an informed consent process. The consent form provides you with details about the study, such as how long the study lasts, what kinds of tasks are involved, and the risks and benefits of participation.

#### What else should I know?

Research is different than medical treatment. Participating in research may not help you individually.

Research studies may offer compensation for participation. Transportation may also be provided.

You are only invited to join a study if you meet the study criteria. Some Registry members may be called for several studies, while other Registry members may never be called for any research studies.

New research opportunities become available on an ongoing basis. Please keep us informed of any<br/>changes to your contact information.Albert Einstein Healthcare Network

Ibert Einstein Healthcare Network Institutional Review Board Approval Date: 1/10/23

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