

Since this research study is not part of your medical care, the only risk to you, if you take part, is the possible disclosure of your Protected Health Information (PHI) without your consent and knowledge. This research study is conducted in full compliance with HIPAA (Health Information Portability and Accountability Act, 1996). Scientists and clinicians who study PHI to learn more about CRPS will NOT be able to know who you are (your name, address, birth date, or other personal “identifier”). Project staff will keep your personal identifiers in a separate, secure file.

Your medical records may become part of the research record. If that happens, your medical records along with your answers to the study questions (**Protected Health Information** or PHI) will be stored in a secure computer and protected from disclosure to anyone other than investigators and project staff.

Here are answers to some important questions about your PHI:

What information may be used and given to others?

The study instruments will contain your personal and medical information (Protected Health Information, PHI). The study instruments include:

- Past and present medical history
- The number and types of treatments
- Records about phone calls made as part of this research

Who may use and give out information about you?

The study investigators and the project staff.

Who might get this information?

- Qualified investigators who agree to comply with the rules and safeguards of this research study. Investigators who are not members of the project staff or a principle investigator, will not receive personal identifiers.

To insure privacy and confidentiality of your PHI, your information may be given to:

- Department of Health and Human Services (DHHS) agencies,
- Governmental agencies concerned with the regulation and enforcement of HIPAA,
- Western Institutional Review Board[®] (WIRB[®])

Why will this information be used and/or given to others?

- to do the research,
- to study the results, and
- to make sure that the research was done right.

If the results of this study are made public, information that identifies you will not be used.

What if I decide not to give permission to use and give out my health information?

Then you will not be able to be in this research study.

May I review or copy my information?

Yes.

May I withdraw or revoke (cancel) my permission?

Yes, but this permission will not stop automatically.

You may withdraw or take away your permission to use and disclose your health information at any time. You do this by sending written notice to the Principle Investigator. If you withdraw your permission, you will not be able to stay in this study.

When you withdraw your permission, no new health information identifying you will be gathered after that date. Information that has already been gathered may still be used and given to others, but your personal identifiers will be removed.

Is my health information protected after it has been given to others?

Your PHI will only be given to certified investigators and project staff who have agreed to comply with the confidentiality rules set up by the research team, approved by WIRB and compliant with HIPAA regulations. There is a risk that your information will be given to others without your permission. The purpose of HIPAA compliance, is to set up a series of safeguards that minimizes the possibility that your information will be given to others improperly.

The results of this research study may be presented at meetings or in publications. Your identity will not be given out during those presentations.