

## **Privacy Policy for Protected Health Information (PHI) in Research (RADIANCE Study)**

**Purpose of Collecting PHI:** This privacy policy outlines the handling of protected health information (PHI) collected for participants in the RADIANCE research study. The PHI is collected to determine eligibility for study participation, conduct the study, and evaluate its results.

**Type of Information Collected:** The following PHI may be collected as part of this study:

- Medical information including SCD diagnosis, genotype, pain levels, medication details, hospital admission dates, laboratory values, and vital signs (blood pressure, respiration rate, pulse, temperature, weight, height). None of this information will be shared via text messages.
- Demographic information such as name, address, phone number, date of birth, gender, ethnicity, marital status, education level, occupation, and income. Only your phone number will be shared via text messages.

**Use of Information:** The collected PHI will be used to:

- Assess SCD diagnosis and type.
- Determine eligibility for participation in the study.
- Ensure the integrity and reliability of the research.

**Storage and Protection of Information:** PHI will be stored securely in locked filing cabinets, on computer servers with secure passwords, or on encrypted electronic storage devices. Stringent security measures are in place to protect the privacy and confidentiality of this information.

**Limited Data Set:** Some of the PHI may be included in a "limited data set" for further research purposes. This data set will exclude direct identifiers such as your name, social security number, and other linking codes.

**Sharing of Information:** PHI may be shared with:

- The study sponsor.
- Governmental agencies overseeing research (e.g., FDA, HHS, OHRP).
- Public health authorities (e.g., CDC, federal/state/local health departments).
- The IRB reviewed this research study ensures your rights as Study subject are protected.
- Data is never sold to any third party, and there is no international transfer of information.

**Third-Party Access:** PHI may be obtained from other healthcare providers involved in your care, whether they are part of this study or not.

**Protection of Rights:** The Research Team and all entities with authorized access to PHI are committed to protecting the rights and privacy of study participants.

**Revocation of Authorization:** Participants have the right to revoke their authorization for the use of their PHI at any time. However, revocation will not affect any information already used or disclosed.

**Legal Requirements and Disclosure:** Identifiable health information will not be disclosed without permission unless required by law or a court order. Please note that once PHI is disclosed to third parties, it may no longer be protected by federal privacy laws and could potentially be redisclosed.

**University of Florida Privacy Policies:** Our research study adheres to the privacy practices as outlined by the University of Florida. For detailed information on how the University of Florida protects your personal information online, and the university's comprehensive privacy policies and procedures, please refer to the UF Online/Internet Privacy Statement available at

<https://privacy.ufl.edu/privacy-policies-and-procedures/onlineinternet-privacy-statement/>

**Contact Information:** For inquiries or concerns regarding participant rights or privacy related to the study, please reach out to the following contact points:

The RADIANCE Study Team

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Address: 1225 Center Drive, PO BOX 100197, Gainesville, FL 32610-0197

Study Email: [radiancestudy@nursing.ufl.edu](mailto:radiancestudy@nursing.ufl.edu)

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Study Coordinator: 352-273-6356

Research Specialist: 352-273-6520

Personal Emails: [greenleeal@ufl.edu](mailto:greenleeal@ufl.edu) , [muntahaali@ufl.edu](mailto:muntahaali@ufl.edu)

We are here to address any questions or concerns you may have regarding your rights or privacy as a participant in the study.