

FANCONI ANEMIA PATIENT REGISTRY

We are pleased to announce the launch of the Fanconi Anemia Registry, a collaborative effort between the Fanconi Anemia Research Fund (FARF) and the National Organization for Rare Disorders (NORD) to study Fanconi anemia (FA).

About the Registry

The Fanconi Anemia Registry is more than a versatile online system that securely collects and stores data for medical research; it is a dynamic participant-driven resource that can empower and unite the FA community through shared knowledge.

Registry participants can complete surveys about their own disease experiences in addition to learning about other participants' experiences by viewing anonymized aggregated survey data. As the registry sponsor, FARF will ensure that data privacy and confidentiality are strictly maintained. Participation in the Fanconi Anemia Registry is free and voluntary, and participants may withdraw at any time.

Community Involvement

The Fanconi Anemia Registry is a powerful opportunity for individuals with FA and their family members to contribute directly to research that will enhance our understanding of the disease, and facilitate the development of new diagnostic and treatment options.

Participation is especially vital given the rarity of FA – every patient experience is a unique and invaluable part of the natural history of FA.

Interested in participating?

Contact Suzanne Planck: 1.541.687.4658 | registrymanager@fanconi.org

