flok | RESEARCH

A longitudinal study that seeks to:

- **Define the systemic phenotype of inherited disorders of protein metabolism across physiological systems and their comorbidities**
- **Understand the heterogeneity of phenotype and its impacts on quality of life (QOL)**
- **Identify aspects of phenotype related to underlying disorder vs treatment side effects of a highly restrictive and synthetic diet**
- **Understand the impacts of lack of standardization of care across the population (e.g. age, sex assigned at birth and gender identity, economic and geographic distribution)**
- **Predict metabolic aberrations (e.g. elevated amino acid levels, impending acute metabolic events)**
- **Predict potential response to therapeutics based on genotype & phenotype**

Study Overview

Purpose

To better understand the lived experience of those with inherited disorders of protein metabolism, characterize how these conditions and their treatments impact health, and improve care by accelerating scientific research.

Procedure

Participants will engage in the study through the use of the flok app (free to download and use).

Duration

The study will run for an indefinite period of time and has no fixed end date. Participants may join or withdraw at any time.

We invite individuals to participate who:

- Have been diagnosed with one of the following:
  - Arginase Deficiency
  - Argininosuccinic Aciduria
  - Citrullinemia
  - Classical Homocystinuria
  - CPS-1 Deficiency
  - Glutaric Acidemia
  - Maple Syrup Urine Disease (MSUD)
  - Methylmalonic Acidemia
  - NAGS Deficiency
  - OTC deficiency
  - Phenylketonuria (PKU)
  - Propionic Acidemia
  - Tyrosinemia
- Are 18 years of age and considered an adult where they live
- Are less than 18 and have the consent of a parent or guardian
- Have access to / use of a mobile phone (Apple or Android)

How to Join

Open or download the **flok app**
On the main menu, visit **Research** > **Manage Consent**

Questions? **support@flok.org**
North Star IRB #**NB500298**
Sponsor: **flok Health**

Scan QR Code or visit
research.flok.org