



## Community Care Fueling Community Research

**Our mission is to rally the inherited metabolic disorder community to continuously improve our care and accelerate scientific progress.**

We serve the inherited disorders of protein metabolism: Classical HCU, MSUD, the Organic Acidemias, PKU, Tyrosinemia and Urea Cycle Disorders.

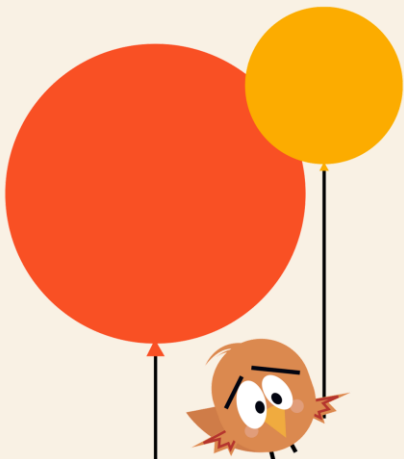


Rare and underrepresented population

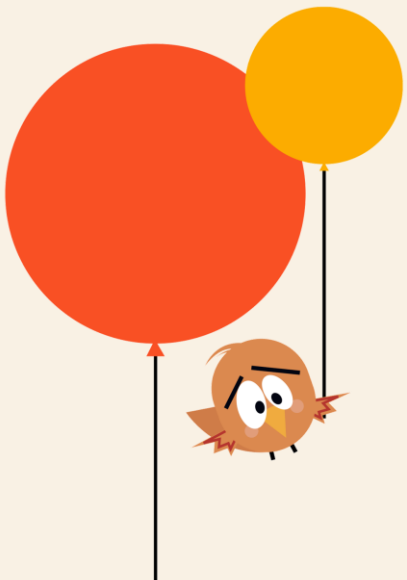
14 genetic disorders

Range of expression and outcomes

Approx 50,000 total in US



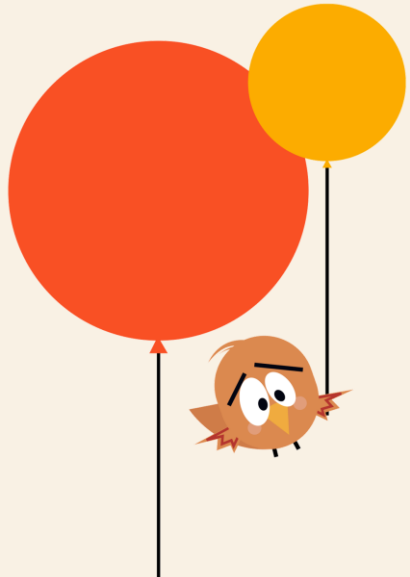
# State of the Art for Our Conditions



- There are no clinical care networks
- There are no clinical registries
- There is insufficient long-term longitudinal data\*
- There are no dedicated centers of research
- Access to dietary treatment not guaranteed
- Many patients are lost to care
- Diet is not a cure
- Understanding of life with these disorders has not advanced significantly in the past 20 years
- The population is aging, and we don't understand what that will look like

*At best, we look like CF in the 1960s (with less \$\$)*

Building on 35 years of service to this community, we're launching a patient-driven effort to transform the data available for research on our conditions via tools that improve daily life and care.



Meeting the Community Where They Are

**Our Community Needs CARE**

**Our Community Seeks SUPPORT**

**Our Community Craves CONNECTION**

**Our Community Deserves PROGRESS**

# Now In Beta: The flok app

## EAT



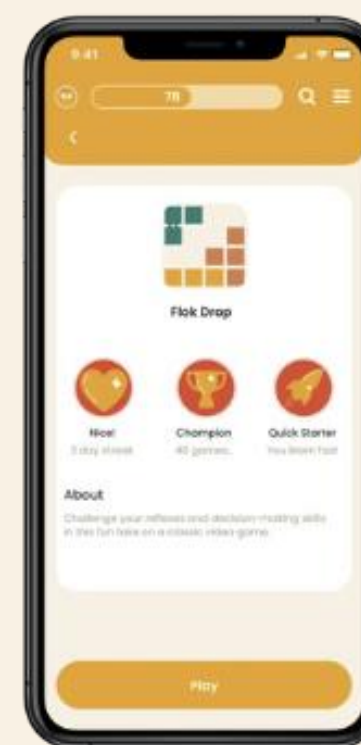
## FEEL



## MOVE

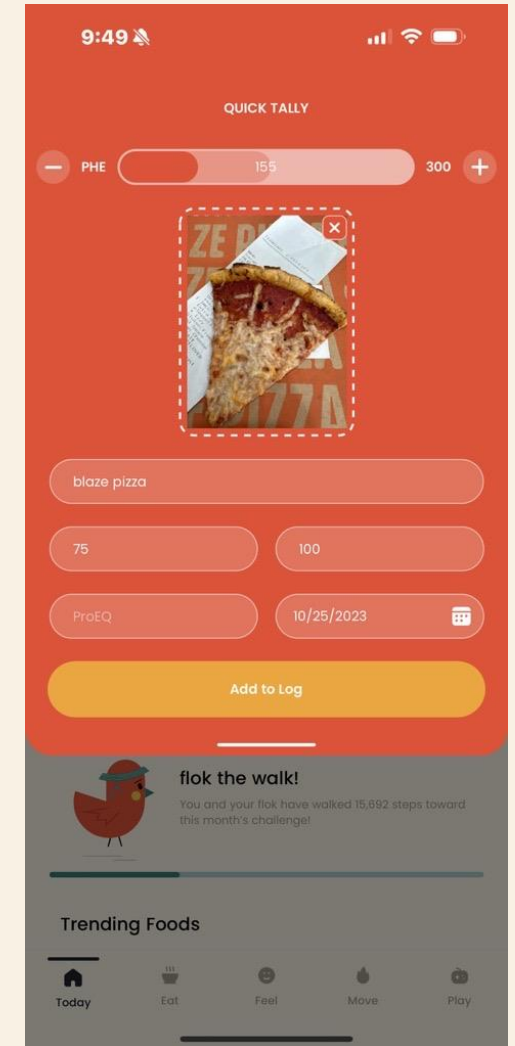
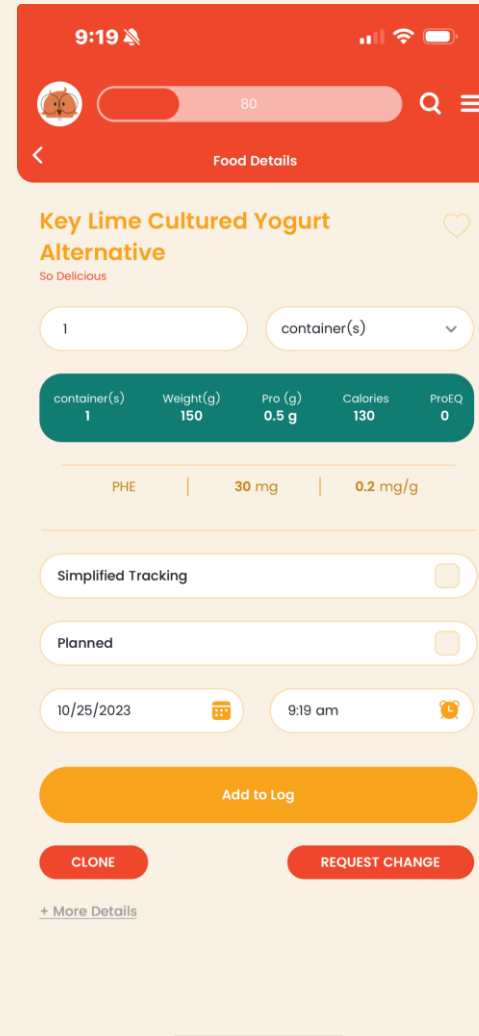
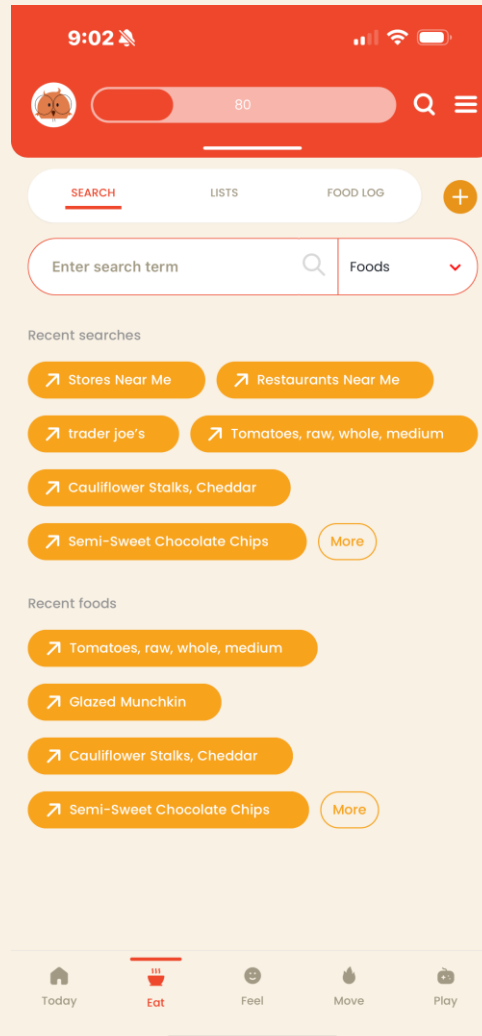


## PLAY



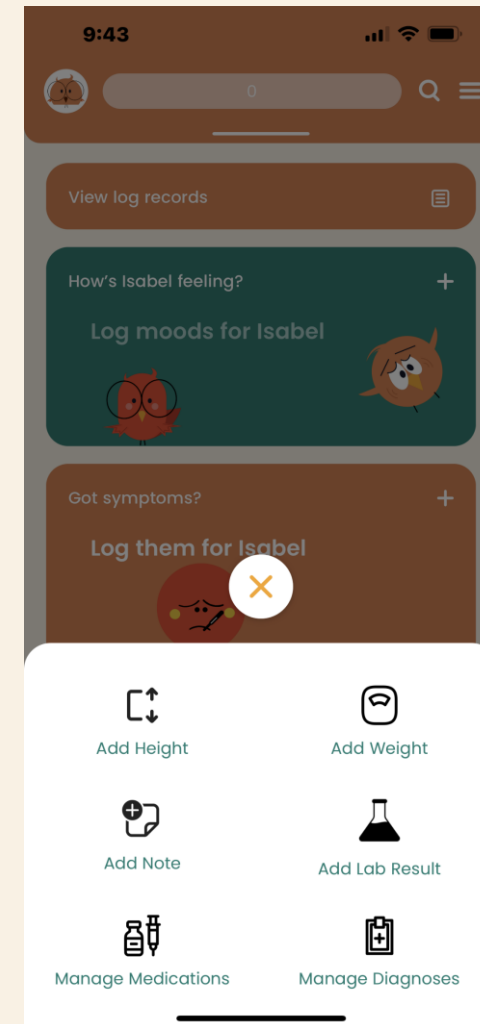
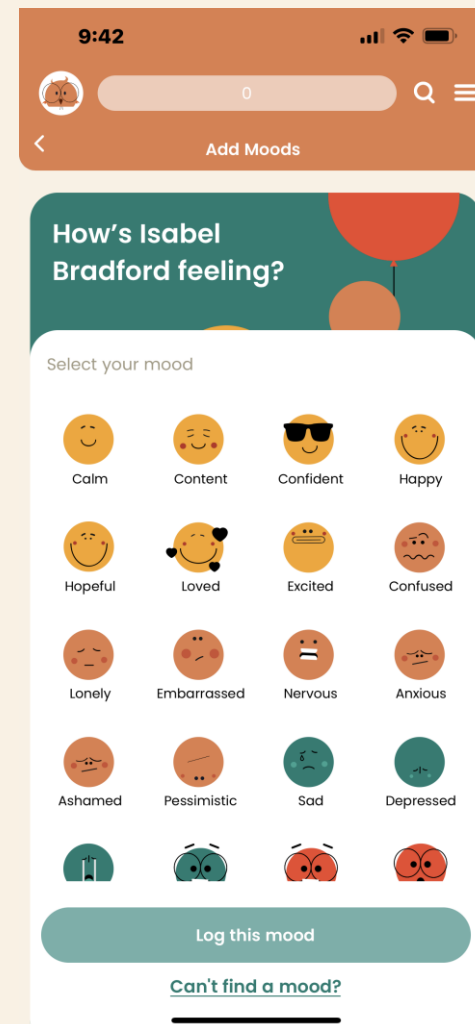
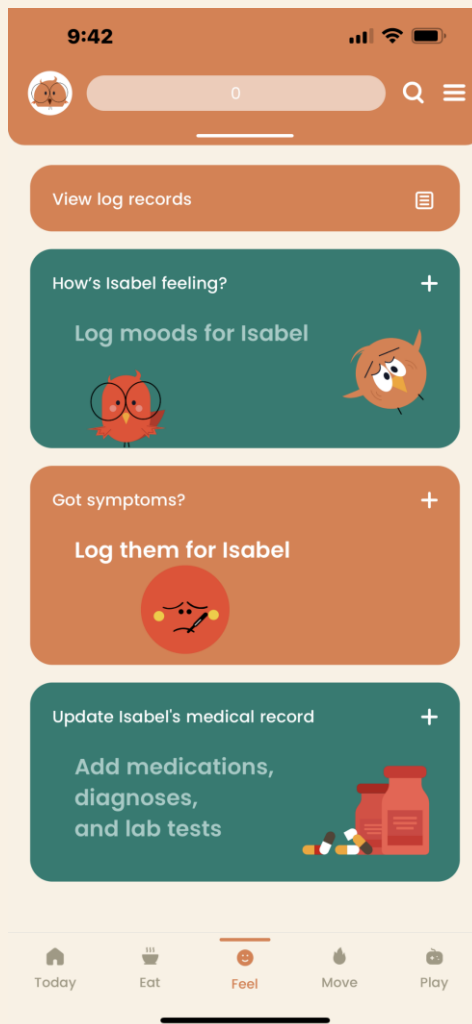
## EAT

- Search foods, recipes, stores, and restaurants
- Record via line-item, quick tally, or photo log
- Kcal, Pro, Isoleucine, Leucine, Lycine, Methionine, Phenylalanine & Valine for 10,000+ foods\*



## FEEL

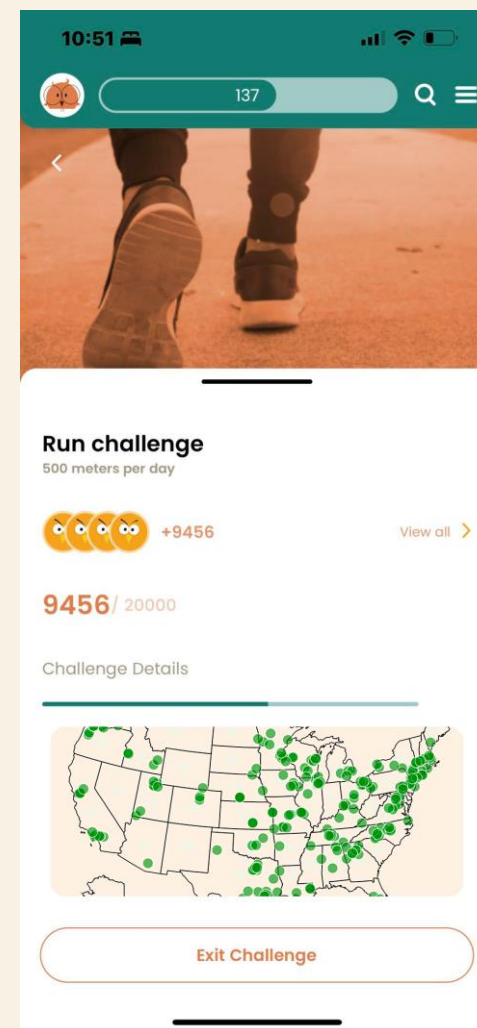
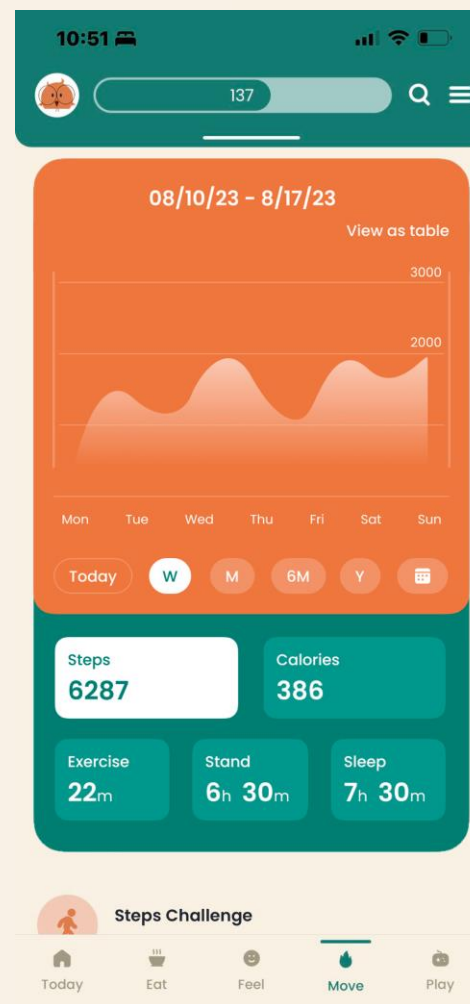
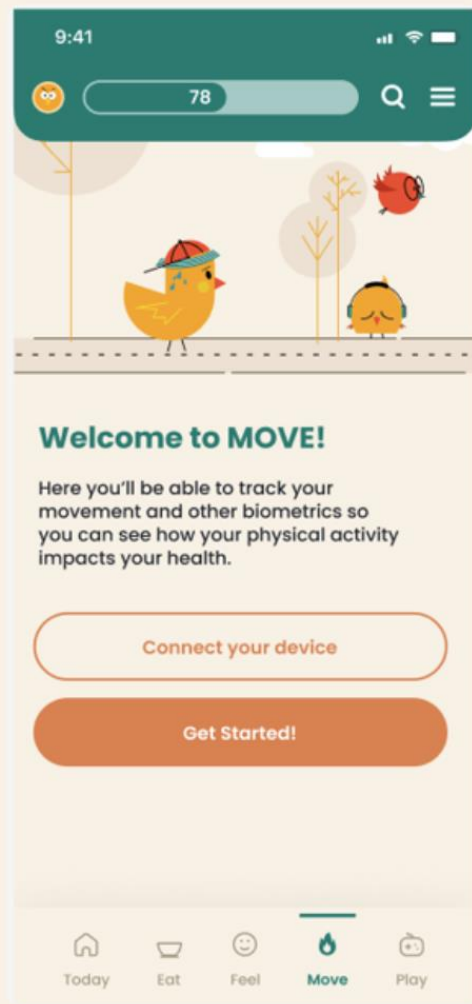
- Record Moods & Symptoms
- Record diagnoses, labs, medications, notes & more
- Potential future integrations
  - EHR (for research only)
  - Home monitors





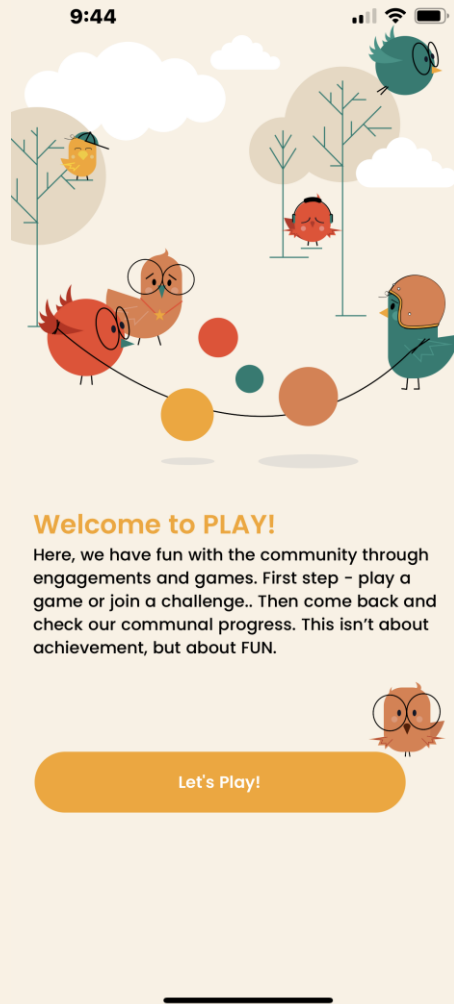
# MOVE

- Track activity
- Join challenges to inspire & build community
- Connect to Apple Watch & FitBit for additional biometric data (sleep, heart rate, temp etc)



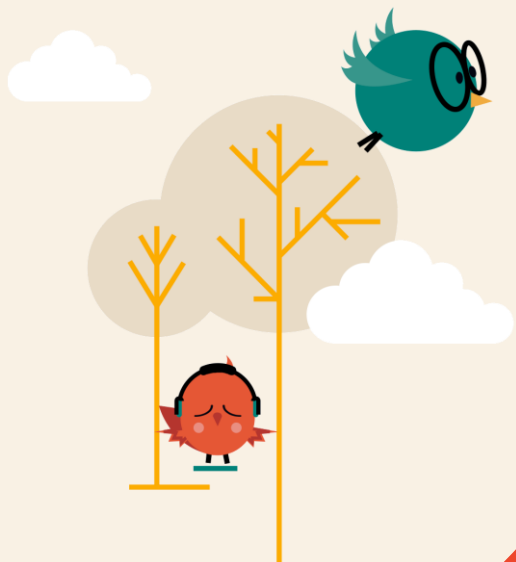
## PLAY

- Play games & join challenges
- Engage with your community\*
- Find Events, News & more ways to connect



\* No direct person-to-person communications are facilitated through the app

# The flok app Can Improve Care



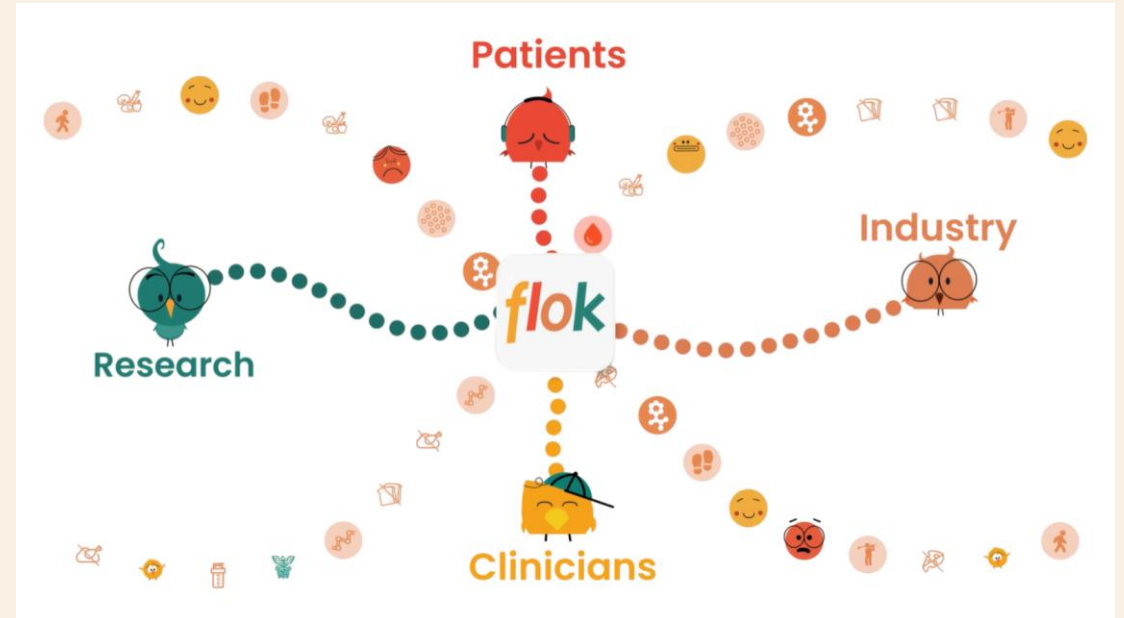
flok

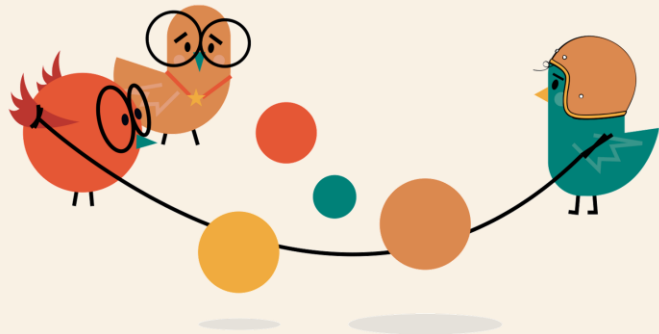
“When I get a call from my dietitian, the first thing she says is ‘**Why do you think your levels are high?**’ and I immediately feel like she’s blaming me, like it’s my fault. **I get defensive, and I shut down.**”

I feel like if she had a report that showed her I haven’t been sleeping well, that I’d been sick or had headaches, and that I was training for a sporting competition, alongside my diet records and blood levels, **she might be able to better understand what was going on, and help me.**” A.S., adult with a metabolic condition

## Driving Progress for Our Community

- Phenotype & Genotype Data on Platform
- Community Investment in Research
- Annual flok natural history reports
- Collaborative research to build models for biomarkers, symptom prediction, and potential interventions
- Comparative reports on clinical outcomes
- Trial management and recruitment features





## **Adult Retreat**

May 28–30, Oregon

## **Family Camp West**

May 30–June 2, Oregon

## **Family Camp East**

Sept 19–22, New Hampshire

Details at [flok.org/camp](https://flok.org/camp)

# Let's Connect!



flok.org

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