

SARAH CHAMBERLIN

sarah@flok.org
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FOUNDER AND EXECUTIVE DIRECTOR, **flok**

Rare disease advocate and parent dedicated to improving the health, daily lives, and futures of those with rare diseases through collaboration and patient-guided research assisted by technology.

PROFESSIONAL EXPERIENCE

flok

Founder and Executive Director

October 2021 - Present

- Community leader dedicated to improving care and accelerating scientific progress in inherited metabolic disorders (IMD)
- Designer & founder of the **flok** app and platform, a non-profit data science platform
- Building a patient-led research network for all inherited metabolic disorders

National PKU News

Executive Director

April 2015 - July 2023 (organization renamed **flok**)

- Developed and manages resources such as PKU pocket books, HowMuchPhe.org, and the GO LOW PRO app
- Grew the reach of Family Camp to 1000 individuals/year
- Built strong social media platform to support all IMD
- Advocates for the PKU community, facilitating patient and clinician collaboration
- Facilitates collaboration among IMD organizations focused on shared goals
- Leader in Medical Nutrition Advocacy

How Much Phe

Co-Founder

January 2014 - Present

- Conceived and developed a platform for dietary management of PKU.

SELECTED PRESENTATIONS AND PROJECTS

Panelist

National Academies of Sciences, Engineering, and Medicine: *Challenges in Supply, Market Competition, and Regulation of Infant Formula in the United States - Downstream Supply Chain* Open Session, December 2023

The Power of Technology to Improve Care and Patient Experience

New England Consortium of Metabolic Programs Annual Meeting, December 2023

Letting Patients Lead: A novel approach to endpoint definition and validation

Break Free of Phe Conference, March 2023

Medical Nutrition Equity Act and The Formula Crisis

New England Consortium of Metabolic Programs Annual Meeting, November 2022

Congressional Testimony: Impact of the Formula Shortage on the Metabolic Community

Testimony to the House Appropriations Committee Subcommittee on Agriculture, Rural Development and the FDA, May, 2022

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SELECTED PRESENTATIONS AND PROJECTS CONT.

It's Not Just a Piece of Cake:

Patient and Clinician Interpretations of the Simplified Diet

Genetic Metabolic Dietitians International Conference, May 2022

Development of MetabolicFormula.org

Response to the Medical Formula Shortage: Played a key role in addressing the challenges faced during the medical formula shortage. Facilitated government, industry, clinician, and patient communication during the 15-month crisis and beyond.

Global Genes Rare Patient Equity Grant Recipient

Developed Spanish-language versions of essential resources for PKU dietary management, May 2021

Covid Care Grant Program

Designed, funded, and executed a program that provided \$88,000 in direct-support grants to individuals and families managing a metabolic disorder whose healthcare was negatively impacted by the Covid-19 pandemic. Coordinated two community-wide surveys on the pandemic's impact on healthcare for those on medical nutrition.

Development of NutritionEquity.org

Conceived and executed web site to support the Patients & Providers for Medical Nutrition Equity, a 45-member coalition working to pass the Medical Nutrition Equity Act. Collected and published stories of hundreds who rely on medical nutrition.

Poster Presentation, Award Winner

Crowdsourcing the Need and the Solution: The GO LOW PRO App
NORD Rare Summit, 2019

Panelist, Eating Well: Taking Care of Yourself Through Nutrition in Rare Disease

Global Genes Rare Patient Advocacy Summit, September 2019

EDUCATION

Indiana University-Purdue University, Indianapolis

Jane Addams Fellowship in Non-Profit Management
Eli Lilly Center on Philanthropy, 1996-1997

Wesleyan University

BA in English Creative Writing, 1992-1996