The ME Association Ramsay Research Fund for Biomedical and Healthcare Research

The faMEly study: A Study of ME/CFS, Family Planning, Pregnancy and Raising Children – A Pilot Study

Grant Amount	£29,880
Location	Newcastle University
Research Field	Healthcare
Lead Researcher/s	Dr Mark Pearce and Dr Emma Slack
Start Date	07/01/2023
Duration	24 months
Status	In progress
Latest Update	The ME Association Pregnancy Study: Would you like to take part?

BACKGROUND

Despite the significant impact of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) on overall health, little research has explored its potential effects on pregnancy outcomes for both the birthing parent and child. This lack of evidence creates uncertainty around family planning, pregnancy, and postpartum care, leaving individuals with ME/CFS and healthcare providers without clear guidelines to inform medical decisions.

The researchers completed a mixed-methods systematic review on ME/CFS and pregnancy, funded by the Newcastle Healthcare Charity. Their findings highlight substantial gaps in knowledge, including:

- The effects of ME/CFS on pregnancy outcomes.
- The impact of pregnancy on ME/CFS severity.
- The attitudes and knowledge of healthcare providers regarding ME/CFS in pregnancy.

- The experiences of ME/CFS patients with family planning, pregnancy, and postnatal care.
- The perspectives of partners supporting individuals with ME/CFS.

A primary study conducted in the U.S. found that ME/CFS worsened in 29% of women during pregnancy and in 50% after pregnancy. Additionally, a potential increased risk of spontaneous abortion, developmental delays, and learning disabilities was noted, though the study did not adjust for maternal age—a key confounding factor. Given this study's limitations (small sample size, lack of adjustment for confounders, and absence of trimester-specific analysis), further research is urgently needed.

Currently, there is almost no UK-specific research on ME/CFS and pregnancy, with only one identified case report (Jha et al., 1999). This scarcity of data means there are no evidence-based clinical guidelines to support informed decision-making on ME/CFS and pregnancy.

PROJECT DETAILS

To address these gaps, this pilot study will:

- Establish research priorities for individuals with ME/CFS and their healthcare providers regarding pregnancy.
- Explore experiences, attitudes, knowledge, and perceptions surrounding ME/CFS and pregnancy.
- Investigate pregnancy decision-making among individuals with ME/CFS and healthcare professionals, including doctors, midwives, and health visitors.
- Identify what data is currently collected in routine medical practice related to ME/CFS and pregnancy to inform future research directions.

The research plans to published in peer-reviewed journals and disseminated at conferences, laying the foundation for a larger research program examining the risk of adverse pregnancy outcomes, prenatal and postnatal care, and the impact of pregnancy on ME/CFS severity and symptoms.

IMPORTANCE OF FUNDING

Funding for this pilot study is critical because:

- **It will guide future research:** This study will set research priorities, ensuring future investigations address the most pressing concerns of ME/CFS patients and clinicians.
- **It will inform evidence-based guidelines:** The lack of established clinical guidelines means patients and healthcare providers are navigating pregnancy decisions with uncertainty. Research is urgently needed to improve care.
- **It will improve healthcare provider education:** Understanding healthcare professionals' knowledge and attitudes will help identify barriers to effective medical support and inform better training.
- **It will enhance patient well-being:** Reliable data will enable individuals with ME/CFS to make informed family planning decisions and receive appropriate medical care during pregnancy.

The ME Association's funding of this research underscores the urgent need for medical advancements in ME/CFS and pregnancy. This pilot study is a critical first step toward developing evidence-based recommendations and improving healthcare outcomes for thousands of individuals.