

Meil Family Foundation 2024 Research Award for Neurocognitive Studies

Providers Involved: David Harrison, MD (graduated ACHD fellowship in 2023), Jamie Jackson, PhD (MAB Member), Anitha John, MD, PhD (Board Certified ACHD Provider and MAB member)

Title: *Psychological trauma and post-traumatic stress disorder in adults with congenital heart disease: What is the scope of the problem?*



Psychological trauma and post-traumatic stress disorder (PTSD) are a known consequence of childhood adversity. Symptoms include feelings of triggers, intrusive memories, and avoidance of activities. In adult congenital heart disease (ACHD), many patients are exposed to stressors in childhood, ranging from open heart surgeries, stigma from their peers, or stress in the family. Despite these risk factors for PTSD, little is understood about which elements of the ACHD patient experience show the strongest association with PTSD. In other words, if we can describe what patient factors are linked with PTSD, we may increase our chances of being able to prevent it.

This study as proposed will aim to partner with the Congenital Heart Initiative—one of the largest available survey registries in ACHD—to use specialized survey tools, including the “gold standard” clinician interview for PTSD diagnosis, with a team of trained facilitators. These methods will help us most accurately measure the overall burden of PTSD in the ACHD population, while also assessing for which patient factors may put one at the greatest risk for developing PTSD.