This proposed project will utilize three key strategies to improve access to quality health care for children and youth with epilepsy (CYE): (1) establishment of a technology-based learning collaborative for epilepsy education of CYE, their families and providers; (2) development of a transition program for adolescents with epilepsy from pediatric to adult specialty care; (3) expansion of a robust medical home-based telemedicine system to incorporate an innovative tiered telemedicine system of care that links community neurologists in rural and medically underserved areas with the Level 4 Pediatric Epilepsy Center at the University of Michigan. The project focuses on improving access for CYE in Michigan’s Upper Peninsula and targeted largely rural and medically underserved areas of the Michigan Lower Peninsula that are identified as health disparity regions.

The project team will develop a robust and inclusive learning collaborative composed of youth in transition, families, and providers. The collaborative will incorporate complementary, technology-based interactions and in-person meetings. A series of webinars will be developed for primary care providers to improve their knowledge regarding common pediatric epilepsy assessment and management. Quality improvement processes will integrate goals to improve the epilepsy knowledge base and system of care through practice change.

Adolescents with epilepsy and their families will participate in a transition program and learning collaborative to support their transition from pediatric to adult epilepsy care. This will be accomplished through a strong collaboration with the Patient Family Center at Mott Children’s Hospital, Ann Arbor, and with a designated adult epileptologist. The transition program will be based on the six core outcomes of the Got Transition program. Beginning at age 12 years, youth and their families will be engaged in assessment and activities to identify individual learning needs that will support self-management and self-efficacy.

The project will expand the scope of our medical home based Pediatric Telemedicine Clinic. In the Michigan Upper Peninsula, the team will engage at least one college-based health center for telemedicine and transition. Involvement of school-based health centers will provide novel opportunities to provide health education, improve access to care and facilitate transition from pediatric to adult care systems. An innovative, tiered system of care will link a community hospital pediatric neurologist with the Level 4 certified Pediatric Epilepsy Center at the University of Michigan through telemedicine. This tiered system will facilitate community-based care, consultative care for complex cases, and improved communications for follow-up treatment and outcome assessment. A comprehensive evaluation program that includes PDSA cycles will be employed to assess the impact of this work on key stakeholder groups: families, providers, and the telemedicine network systems.