

The Advanced Cardiac Therapies Improving Outcomes Network (ACTION) will improve critical outcomes for children with heart failure by developing an international quality improvement network that unites providers and families.

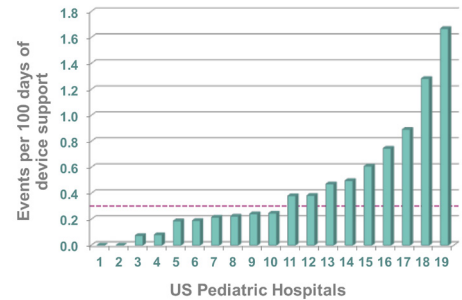


Figure 1. Extreme variability in the rates of stroke amongst US Pediatric hospitals.

“By pooling our resources and experiences we can learn from center variation and will be able to improve the outcomes of patients with heart disease across all centers.”

Angela Lorts, MD

Co-Leader, ACTION, Medical Director, VAD/TAH Program, Cincinnati Children’s Hospital Medical Center

Our Background

Pediatric heart failure is characterized by high severity of illness (mortality associated with pediatric heart failure is among the highest of any cardiac condition), but due to the small number of affected children, there are few published data to support care decisions. Expertise is difficult to develop due to the small numbers of patients at any one center, and the inherent variability of the disease. Caring for this complex patient population requires a collaborative, multi-institutional approach to improve the outcomes of these children.

One benefit achieved by working together is the improvements we could make in the outcomes of children on ventricular assist devices. In the current era, 15–30% of all children will suffer a stroke when supported on a VAD. In many cases this may be fatal or lead to a poor neurological outcome. However, there is a significant amount of variation in stroke rates between institutions (figure 1). This is thought to be driven by center volume and experience. This suggests that there is an opportunity to identify and implement best practices from those centers that have lower stroke rates, in order to improve the outcomes for children treated at all centers. Traditional models of clinical trials have well-known limitations in dealing with rare diseases such as heart failure in children. While trials can address specific questions and are instrumental in validating critical treatments, they leave many questions unanswered.

Our Approach

Harnessing the power of a collaborative Learning Health System, the pediatric heart failure collaborative will practice methodology aligned with the Model for Improvement (an improvement science method developed

and endorsed by the Institute for Healthcare Improvement). Patients, clinicians and researchers will use this approach to engage cardiology teams throughout the Collaborative, and to help centers learn from one another. This model promotes the use of rapid Plan-Do-Study-Act (PDSA) cycles where care teams address problems by testing interventions and subsequent modifications in small steps to achieve desired change.

A Learning Health System is defined as a system in which healthcare, continuous improvement, technological innovation, and research are all purposefully integrated. This is “designed to generate and apply the best evidence for the collaborative choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care.” Such an approach can drive improvement in areas that are untouched by clinical trials alone.

The Learning Health System vision is especially relevant to children with chronic diseases, most of which meet the NIH definition of a rare disease. Achieving the vision for a network caring for rare diseases, however, requires a method to connect care centers that are widely distributed geographically. Networks are particularly important for chronic childhood disease because no single center has a sufficient number of patients to produce generalizable knowledge, a barrier that can slow the pace of knowledge acquisition and outcomes improvement. In recent years, evidence has accumulated that demonstrates how collaborative pediatric research networks can achieve marked improvement in the quality of care, safety and outcomes of children. Effective networks have an unrelenting commitment to collecting high quality data, continuously evaluating and proving their value to participants, and engaging clinicians and their institutions to sustain their work over time.

Our Locations

We are excited to have over 20+ network locations and counting! Please visit our website at: actionlearningnetwork.org for a complete up-to-date list of all our participating locations.

Our Goals

The overarching goal of the Pediatric Heart Failure Collaborative is to improve outcomes for children with heart failure. While the initial project will focus specifically on improving the outcomes of children that are being treated with ventricular assist devices, we anticipate extending the scope of work to next include other aspects of treatment of acute heart failure. Over time, we hope to include children with more chronic forms of heart failure.



“Being the Parent Lead with Action is an empowering feeling. Living in the hospital with my son both pre and post stroke and transplant allows me to share our experiences with others. The ultimate goal of Action is to improve outcomes. Including parents in this collaboration is a key factor in obtaining that goal. I am honored to be a part of something near and dear to my heart working with individuals who share my passion.”

Carolynn

Parent, pictured above with son, Liam