After 20 years of training in-country cardiac specialists and building the capacity of hospitals to treat children with heart disease, Children’s HeartLink has some important lessons about what it takes to make a difference. Workforce development, financing for congenital heart surgery, adequate screening and diagnosis, and data on the prevalence of congenital heart disease are all critical to hospitals being able to improve their heart care. In order to address these issues, Children’s HeartLink has focused on the infrastructure for pediatric cardiac care – to benefit the hospitals we work with, as well as the entire region they serve.

Children’s HeartLink has initiated a number of partnerships with health organizations and health policymakers in India, where we have provided pediatric cardiac training since 1998. These partnerships strengthen health systems in the country through:

- **Training front-line health professionals** from the regions surrounding our partner hospitals, to improve community-based screening, timely referral and care coordination with treatment centers;
- **Empowering medical professionals** not only to diagnose and treat, but also to advocate on behalf of children with heart disease;
- **Engaging key regional and national decision makers** to develop supportive practices, policies and laws that will facilitate access to pediatric cardiac care.

This strategy seeks to influence the barriers impeding access to health care for children and ultimately ensure that high-quality care is accessible to all children in need. Barriers include: late diagnosis and late referral to heart specialists, inaccessible and costly transportation to hospitals, high treatment costs, and a limited understanding of congenital heart disease from policymakers and health systems planners.
Kerala: Improving Access to Quality Care

In partnership with the Government of Kerala since 2017, Children’s HeartLink has employed a regional, population-level approach designed to significantly improve access to quality care for children with congenital heart disease. This complements our existing efforts to build sustainable regional centers of excellence in the country.

We chose Kerala as one of the regions to pilot this work because Children’s HeartLink Center of Excellence Amrita Institute of Medical Sciences is located there and can be used as a referral center and regional training resource for other hospitals to build capacity. Kerala is also the state with the lowest infant mortality rate in India, and after the approval of the United Nations Sustainable Development Goals, the Kerala government set a goal of further reducing its infant mortality rate from 12 to 8 per 1,000 by 2020, focusing on congenital heart disease as one of the main contributors.

This partnership has improved the system for prenatal, newborn and childhood screening of congenital heart disease through training and awareness-building among primary care providers and specialists working with mothers and children in Kerala. In February 2019 the Kerala government announced that it will initiate mandatory newborn screening in the state by 2020.

Additionally, the state government has developed a unique online registration system named Hridyam to manage the detection and referral of patients with congenital heart disease. The first system of its kind in a low- or middle-income country, Hridyam monitors the patient diagnosis and treatment progress and leads to faster medical referral of patients with critical congenital heart disease.

Our Indian Partners in Health Systems Strengthening

India Academy of Pediatrics
Since 2011, Children’s HeartLink has collaborated with the state chapters of India Academy of Pediatrics to provide education for pediatricians on early detection and community-based follow-up care for patients with congenital heart defects.

National Board of Examinations and People4People
The National Board of Examinations is the national body that sets standards in India for post-graduate medical education. Since 2011, Children’s HeartLink and People4People, a Bangalore-based nonprofit organization, have collaborated with the National Board of Examinations to improve and expand training for pediatric cardiology fellows by using an online e-learning platform developed by People4People for weekly live classes.

Pediatric Cardiac Society of India
Children’s HeartLink has partnered with the Pediatric Cardiac Society of India since 2013 to promote nurses as integral members of the pediatric cardiac team through organizing the nursing professional track during the society’s annual scientific meeting.

Our US Partners in Health Systems Strengthening

Newborn Foundation
The Newborn Foundation is dedicated to leveraging technology innovation to improve health outcomes for newborns, including pulse oximetry testing to detect congenital heart defects. The Newborn Foundation provides the initial assessment and education of labor and delivery center providers for newborn screening and supports implementation of newborn screening globally.