



What is the Pediatric Heart Network (PHN)?

The Pediatric Heart Network (PHN) is a collaboration of clinical sites and a data coordinating center that conducts research studies in children with *congenital* or *acquired heart disease*. The PHN was created and funded in 2001 by the [National Heart, Lung and Blood Institute](#) to improve outcomes and quality of life in children with heart disease. *Centers* with experienced research teams at hospitals that specialize in the care of pediatrics patients with heart disease were chosen to become part of the PHN.

Congenital cardiovascular malformations affect approximately 40,000 infants in the United States each year, and are a leading cause of infant death. The incidence of congenital heart disease is at least triple that of childhood cancers, and is substantially greater than pediatric AIDS. Yet very little research has been conducted in pediatric heart disease. In the past 25 years, fewer than 40 randomized clinical trials have been carried out in patients with congenital or acquired heart disease and nearly half of these dealt only with a patent ductus arteriosus in preterm infants.

The major barriers to clinical studies in pediatric heart disease include small numbers of individuals with a particular congenital heart defect at any one center, differences in treatment approaches and lack of resources to provide national coordination of collaborative research. Additional barriers relate to parents being unaware of studies, living a distance from a research site or lacking familiarity with what happens during a study.

The Network approach attempts to address these barriers by offering an effective, flexible way to study adequate numbers of patients with uncommon diseases through a common infrastructure for recruiting, monitoring, and following patients whose conditions will be characterized in a standard fashion.

All of the centers carefully follow a *study protocol*, collect identical data and treat patients in similar ways. (See [How Studies are Created and Monitored](#)). The PHN centers use similar brochures and consent forms. Research teams have been trained in Human Subjects Research as required by the [National Institutes of Health \(NIH\)](#) as well as trained in study conduct for each protocol in the PHN.

As a healthcare provider, you may wish to discuss a study with one of your patients or refer a patient for consideration for study enrollment. Study requirements, inclusion/exclusion criteria, endpoints and general protocol information can be found in "[Current Studies](#)". Patients referred to a PHN study continue to be managed by their primary cardiologist. Arrangements will be made to allow the PHN research team to interact frequently with the primary cardiologist in order to coordinate tests or visits and to ascertain adverse events. Referring a patient and their family to a research study has the potential to increase their healthcare monitoring and will involve you as part of the subject's primary medical caregiver.

[How Studies Are Created and Monitored](#) ➔



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