



What is the Pediatric Heart Network (PHN)?

The Pediatric Heart Network (PHN) is a group of hospitals in the United States and Canada that conducts research studies in children with *congenital* or *acquired heart disease*. Congenital heart defects occur in approximately 40,000 infants in the US each year and are a major cause of infant death. Acquired heart disease can cause death and long-term disability.

In the past 25 years, fewer than 40 *randomized clinical trials* have been done in patients with congenital or acquired heart disease. There are several reasons for this. Many hospitals or single doctors do not see enough children with any one type of heart disease in order to perform certain studies and have meaningful results. Parents have been unable to enter their children into studies because they are not aware of them, they don't live near a research site or may not feel at ease about what happens during a study.

The PHN was started in 2001 by the [National Heart, Lung and Blood Institute](#) to study problems in children with heart disease. Nine studies have been done since 2001 at children's hospitals with research teams that specialize in the care of patients with heart disease. All centers do the same studies. This helps to increase the total number of patients needed for each study. When studies need more patients than the main centers have, other skilled centers may be trained in one or more studies. (See "[PHN Sites](#)")

All of the centers carefully follow a *study protocol* and treat patients in similar ways so that the study results are accurate. The PHN centers use similar brochures and *consent forms* to share with families who may want to enter a study. Patient safety is a high priority when a study is being planned and done. (See "[Ensuring Safety in PHN Trials](#)".)


PHN nurses and doctors are skilled in the care of children with heart disease **and** in the conduct of clinical studies. They have had special training in doing research in ways that help to protect patients in a study. They also have training in how to conduct the specific PHN studies and are sensitive to families with sick children. They can be a good resource for you as you decide whether to allow your child to enter one of the PHN studies.



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 = glossary definition

Why Include Children in Research? 

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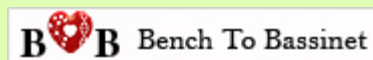
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