

PUSHING CDH CARE TO NEW FRONTIERS



Imagine finding out when you're pregnant that your child will be born with a life-threatening condition, and that when they are born, they will struggle to breathe. Over the past 25 years, Children's Hospital of Philadelphia has established the very best program in the world to treat that condition, known as congenital diaphragmatic hernia (CDH). CHOP sees, by far, the most patients with CDH of any program in the world, and what they learn allows them to make breakthroughs to improve care and long-term outcomes.



WHAT IS CONGENITAL DIAPHRAGMATIC HERNIA?

Congenital diaphragmatic hernia (CDH) occurs when the diaphragm, the muscle that separates the chest from the abdomen, fails to close during prenatal development. This opening allows the abdominal organs (stomach, intestines and/or liver) to move up into the chest, threatening the growth of the lungs. The lungs will be smaller than expected (pulmonary hypoplasia), and they will have less developed blood vessels. This causes high blood pressure in the lungs (pulmonary hypertension).

WHAT CAUSES CDH?

The cause of CDH is unknown. Typically, CDH is an isolated finding although it can occur along with heart disease or a genetic abnormality which can lead to additional complications. CHOP is engaged in active research projects seeking to better understand the associations and causes of CDH. Genetic researchers are using innovative techniques to try to find the potential underlying genetic etiology of CDH. Identifying the genetic cause(s) of CDH will allow clinicians to better manage and counsel families with an affected child.

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**Children's Hospital
of Philadelphia®**

Richard D. Wood Jr.
Center for Fetal Diagnosis & Treatment



FINDING HOPE AT CHOP

Michael Jr. was one of the Center for Fetal Diagnosis and Treatment's first patients, where he had surgery to repair a CDH.

Amazing things are on the horizon, and as CHOP continues to care for babies with CDH, they continue to learn — and apply that knowledge to improving the future for children and families.

FOR MORE INFORMATION

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TREATMENT OF CDH

For babies born with CDH, every little detail matters and can impact their outcome. It is important that a baby be treated by a team with experience caring for babies with CDH. CHOP sees nearly 50 babies with CDH every year — more than any center in the U.S.

In addition to surgical repair of the hole in the diaphragm, a baby's CDH treatment may include specialized equipment such as an oscillator ventilator, a heart lung machine (ECMO) or nitric oxide. Children also may suffer long-term problems with breathing, feeding, heart function, hearing and brain development. These children may also require expert follow-up care for years to manage pulmonary hypoplasia, or small lungs, and other health issues associated with CDH.

Even if babies don't need these options, it is important that they have immediate access to them when necessary.

ADVANCING BREAKTHROUGHS

CHOP's dedicated CDH treatment team has spent nearly three decades translating research findings into advances that have improved care and outcomes. This team was recently recognized as a CHOP Frontier Program, a designation that supports our ongoing research efforts. The team is focused on optimizing all phases of CDH care clinically, from diagnosis through long-term follow up. The Pulmonary Hypoplasia Program (PHP) — created in 2004 — currently follows more than 1,000 children with CDH well after they are discharged from the NICU.

Inspired by patients and their families, and supported by generous donors, CHOP has built the most robust research program dedicated to innovating care. The team's researchers continue to study the molecular and genetic factors that cause CDH. They are on the cusp of revolutionary advances — from a more effective and safer form of ECMO to a new way of ventilating premature babies that is less harmful to their lungs.