

Newborns don tiny red caps to raise awareness of heart defects

By AMERICAN HEART ASSOCIATION NEWS



Photo courtesy of Northwestern Medicine

For thousands of newborns, it's their first time to "go red," sporting hand-knit red caps delivered to parents at hospitals nationwide.

The tiny accessories are part of the Little Hats, Big Hearts campaign launched by the American Heart Association in 2014 to raise awareness about congenital heart defects and heart disease. The program started in Chicago and has since expanded to 33 states and more than 400 hospitals. More than 90,000 caps are expected to be distributed during February, which is American Heart Month.

About 40,000 babies born each year in the U.S. have a congenital heart defect. It is the most common type of birth defect and the leading cause of defect-related infant illness and death, according to the Centers for Disease Control and Prevention.

Better diagnosis and treatment has allowed more children with heart defects to reach adulthood. As of 2010, about 2 million infants, children and adults are living with congenital heart defects, according to a study in the *Journal of the American College of Cardiology*.

Nurses present the caps and educational materials to parents after they've settled into a hospital room after delivery, said Stefanie House, R.N., head of obstetrics at Advocate Illinois Masonic Medical Center in Chicago. Babies wear them after their first bath.

The caps often spark questions from parents about congenital heart defects, which House's hospital screens every newborn for 24 hours after birth, using a noninvasive pulse oximetry test.



Photo courtesy of Ann & Robert H. Lurie Children's Hospital of Chicago

Babies in the neonatal intensive care unit also receive red caps, which hits a little closer to home for those parents, House said.

Kelli Carlson knows what the NICU parents are going through, describing her own “moment of impact” a decade ago when she learned her newborn had a heart issue.

After a nurse didn’t return her son Will to his hospital room, Carlson knew something was wrong. He had been taken to the NICU with an irregular heartbeat.



Photo courtesy of Loyola Medicine

Carlson later learned he had Wolff-Parkinson-White, a syndrome that disrupts the heart’s electrical signals, leading to brief episodes of a very fast heartbeat. Will was also born with a defective mitral valve.

“You’re always expecting the other shoe to drop,” said Carlson, who lives in Pawtucket, Rhode Island. “When my daughter’s sick, she’s just sick. When he’s sick, it’s more serious.”

Carlson’s local support group, part of Mended Little Hearts, have participated in Little Hats, Big Hearts since it began. She wants families to know where to turn for information about heart disease, something she had to find on her own.

Carlson isn’t a knitter but has secured yarn donations and washes and packages hats for

delivery.

Heather McHenry knits caps and encourages others to take part in Little Hats, Big Hearts by sharing her son Grayson’s experience.

“We’re big on spreading the word because you never know how that awareness is going to spring up,” said McHenry of Pearland, Texas.

Now 5 years old, Grayson was born with no right ear canal and a deformed right ear caused by a rare syndrome that also affects his kidneys.

His heart defects were diagnosed later.

Despite frequent visits to craniofacial and hearing specialists, it wasn’t until his pediatrician detected a slight heart murmur when Grayson was 18 months old that he was referred to a pediatric cardiologist, “as a precaution.”

McHenry recalls laughing when the cardiovascular nurse told her Grayson needed immediate open-heart surgery. The news was so unexpected — her son seemed healthy. Doctors repaired three holes in his heart that were nearly undetectable by a stethoscope because they were so large. Grayson also has a collapsed mitral valve.

Grayson’s 3-year-old sister has a milder form of the syndrome and a slight heart murmur.

McHenry left her job to shuttle her son to therapy appointments four times a week and now homeschools Grayson, who has a genius level IQ and learned how to read at age 2.



Photo courtesy of Northwestern Medicine

“Your life shifts in a moment,” McHenry said of Grayson’s diagnosis. “No one else knows what you go through – that’s the hardest part.”