

MORE THAN HALF OF ALL PARENTS OF CHILDREN WITH CONGENITAL HEART DEFECTS ARE UNINFORMED ABOUT THEIR CHILDREN'S FUTURE CARE NEEDS

Results of Multi-Center Congenital Heart Disease Study Presented at ACC.10 – The American College of Cardiology's Annual Scientific Sessions

PHILADELPHIA – March 16 – The Adult Congenital Heart Association (ACHA), in partnership with the Adult Congenital Care Cardiac Associates (ACCCA), presented the findings of a multi-center congenital heart disease study at ACC.10 yesterday, that show more than half of parents of children with congenital heart disease (CHD) do not understand the need for their children to receive life-long care by adult CHD specialists at an Adult Congenital Heart Disease (ACHD) center.

The “Parental Knowledge” study surveyed 492 parents of children with certain congenital heart defects from nine pediatric congenital heart centers nationwide. More than half of these parents were found to have incomplete knowledge of their children’s future specialized health care needs.

More than one million adults in the United States live with congenital heart disease. Nearly half of them require life-long cardiac care from an ACHD specialist, yet only a fraction of that population actually receives it. Studies have shown that gaps in specialized care can last 10 years or more and may result in adverse health outcomes.

“A lapse in specialized care for people living with CHD likely includes a lack of education about their condition,” said Amy Verstappen, president and CEO of the ACHA. “It remains very difficult for us to reach out to people who have been lost to care, so we place a great importance on educating parents and families to ensure more children with CHD grow up receiving the lifelong treatment they need.”

When the Parental Knowledge survey is complete, the ACCCA and the ACHA will begin the “Life-Long Cardiac Care” educational campaign. Brochures and posters will be distributed at the research sites, as well as at other pediatric heart centers, a network of parent support groups, and online CHD-related chat rooms.

“Ninety-six percent of parents surveyed in the Parental Knowledge study were interested in learning more about their children’s future care,” said Sue Fernandes, PA-C at Children’s Hospital Boston, and the coordinator of the study. “This provides us with an excellent opportunity to develop an educational campaign and future research projects to ensure we are targeting the population most at risk of being lost to specialized cardiac care.”

Facts About Congenital Heart Disease:

- In the United States, 1 out of every 100 babies is born with a heart defect.
- Congenital heart disease is the #1 birth defect with more occurrences than Spina Bifida, Down syndrome or hearing loss, yet many are not aware of this condition.

- In most cases, scientists do not know the cause but feel both environmental and genetic factors appear to play a role.
- Today, most heart defects can be corrected or helped with surgery, medicine, or devices, such as artificial valves and pacemakers.
- In the last 25 years, advances in treatment of heart defects have enabled half a million U.S. children with significant heart defects to survive into adulthood.

About the Adult Congenital Heart Association:

The Adult Congenital Heart Association (ACHA) is a national not-for-profit organization dedicated to improving the quality of life and extending the lives of adults with congenital heart defects (CHD). ACHA serves and supports the more than one million adults with congenital heart defects, their families and the medical community—working with them to address the unmet needs of the long-term survivors of congenital heart defects through education, outreach, advocacy, and promotion of ACHD research. For more information about the Adult Congenital Heart Association, contact (888) 921-ACHA, or visit www.achaheart.org.

About the Adult Congenital Care Cardiac Associates:

The Adult Congenital Care Cardiac Associates (ACCCA) is an organization that brings together ACHD nurses, physician assistants, medical social workers, and psychologists to execute congenital heart research.

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