



Contact:

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## Fund Health Education and Research in Adult Congenital Heart Disease

The success of childhood cardiac surgery has created a new chronic disease—congenital heart disease. Federal funding for ACHD research and education will help prevent premature death and disability in this rapidly-growing and severely underserved population.

### Congenital Heart Defects—This Country's #1 Birth Defect

One out of 120 babies is born with a congenital heart defect, a heart malformation present at birth. Thanks to surgical and medical breakthroughs, today more than 90% of these children are expected to live to adulthood. There are about 800,000 children and 1 million adults in the United States now living with congenital heart disease. As this first generation reaches child-bearing age, genetic studies should be undertaken to learn more about what causes heart defects and how they might be prevented.

### Surgery Is Not a Cure

For the first time in history, there are more adults than children with congenital heart disease, and the number of adults is growing by 5% a year. But as they age, many face a high risk of developing new problems. Many will need re-operations and/or transplant. Because of their abnormal anatomy, experts recommend that at least half of those living with heart defects receive life-long care from congenital heart specialists. Congenital heart defects are a new chronic disease.

### From Medical Excellence to Medical Neglect

Pediatric heart care in this country is excellent, but little provision has been made for the care of the long-term survivors. Doctors, patients, and families alike often mistakenly see these patients as “fixed” and do not seek appropriate follow-up. Most adult cardiologists are untrained in their anatomy and special needs. In 2001, an American College of Cardiology (ACC) report stated that long-term heart defect survivors, a community created by medical excellence, receive the worst care of all cardiac patients. Less than 10% of adult survivors are currently receiving recommended care.

### ACHD Research—Bringing Congenital Heart Care into the 21st Century

A major triumph of 20th century medicine was turning blue babies pink, but now we face new challenges: How can we ensure that these babies live as long as they possibly can? How can we prevent heart birth defects in future generations? **In 2004 a National Heart, Lung, and Blood Institute (NHLBI) expert committee called for federal outreach and research efforts to find and study this first generation of heart defect survivors.** Data on long-term outcomes will provide vital information for the care of infants, children, and adults alike. Please help us bring congenital heart care into the 21st century.

#### **MESSAGE TO CONGRESS—PLEASE INSERT THE FOLLOWING IN THE 2008 BUDGET:**

***Congenital Heart Disease:*** The Committee recognizes that congenital heart disease is a new chronic disease affecting 1.8 million Americans. It commends the NHLBI for convening a working group to address this issue, and supports its recommendation that action be taken to prevent needless disability and premature mortality in this rapidly-growing population. The Committee urges the NHLBI to work with patient associations and other appropriate public health agencies to develop education and research initiatives targeted to the life-long needs of congenital heart defect survivors.

For more information e-mail [info@achaheart.org](mailto:info@achaheart.org) or visit [www.achaheart.org](http://www.achaheart.org).

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## Congenital Heart Defect Fact Sheet

- Congenital heart defects are in-born problems with the heart's structure. Common problems include a hole in the heart and/or parts of the heart that are too big, too small, missing, malformed, or in the wrong place.
- Congenital heart defects are the most common group of birth defects and affect about one in 120 births.
- There are an estimated 1.8 million Americans living with congenital heart defects. One million are over age 18.
- Due to the success of childhood surgeries, more than 90% of those born with heart defects now are expected to live to adulthood.
- The number of adults with heart defects is rising by ~5% a year.
- Surgery is rarely a cure. All heart defect survivors have a life-long risk of additional heart problems. Many heart defect survivors require multiple re-operations as they age.
- 50% of all heart defect survivors have more complex problems and should receive life-long special care to protect heart function and preserve health.
- Many patients and families misunderstand surgery as a cure. Few survivors are aware of their high risk of additional problems as they age.
- Less than 10% of adult heart defect survivors are currently receiving recommended care. Delays in care can result in premature death and disability, often during prime wage-earning years.
- Large numbers of heart defect survivors are now having children. It is the most common heart problem in pregnant women.
- Currently there are no federally-funded national health education or research programs targeting outcomes, needs, or genetics in adult congenital heart defect survivors and their offspring.

More questions? Visit us on-line at [www.achaheart.org](http://www.achaheart.org), e-mail us at [info@achaheart.org](mailto:info@achaheart.org), or call us toll-free at (888) 921-ACHA.

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