



Steve Catoe
9/6/1966-11/28/2010
Tricuspid Atresia

WHO ARE WE?

(This says it all)- thank you, Steve!

Start counting... we're roughly 8 out of every 1,000 people (or 1 out of every 125, if you want a number you can get your head around.) We represent both genders and we are all ages. A million of us are adults, and about 800,000 of us are children.

We've made it through surgeries, hospital stays, infections, endocarditis (infection of the heart), pacemakers, and heaven knows what else. We've given gallons of blood, one vial at a time. We've fought back against tremendous odds. We've been so sick that we've scared the world's best doctors witless... and then amazed them even more when we've fought back.

We've celebrated our victories and we've mourned our losses. We know that most of those who came before us died, including 14 of the first 70 to have the Blalock-Taussig Shunt. We know that most of us shouldn't even be here and so we live every moment as if it is our last - because it could be.

We're Cardiac Kids and Heart Warriors. We have an amazing inner strength, but we are terribly fragile at the same time. We refer to our parents as Heart Dad and Heart Mom, and we use those titles as Badges of Honor. Why? Because they DESERVE them! They were the first ones to discover that a heart defect doesn't just break one heart, it breaks three.

We work, we play, we pay our taxes and we live our lives. We're in your community, in your church, in your school, in your office, and quite possibly in your home. We move a little slower, do some things a little differently, but we usually get along without causing a fuss.

We are people living with Congenital Heart Defects.

Steve Catoe
 South Carolina



Luke-5/12/94-8/8/06 Hypoplastic right heart Syndrome; Tarynn-2/5/09 Truncus Arteriosis; Brooklyn-due 5/26/09-tetralogy of fallot; Shawn-21 yrs old; tetralogy of fallot; Zak-Ebstein's Anomaly; Aoife-2/26/06 Truncus Arteriosis; John-9/29/87- tetralogy of fallot

Mission Statement

Kids With Heart National Association for Children's Heart Disorders, Inc. is a not-for-profit corporation organized to provide support, education and informational materials to families of children who have heart disorders, both congenital and/or acquired in childhood, to assist them in making decisions regarding their child's care.

We maintain a National Database of over 5000 families affected by congenital heart defects, whether they are adult congenital heart defect survivors, families of children with congenital heart defects, or even families who have lost their child to a congenital heart defect.

Utilizing our database, we are pursuing a goal of getting Congenital Heart Defects recognized as the #1 birth defect among the general public as well as the leading cause of death from birth defects.

We are striving to achieve these goals by networking all local support groups nationwide. For this purpose, we maintain a National Database of Local Support Groups for Congenital Heart Defects and link families to one in their area.

Kids with Heart NACHD, Inc. is funded totally on private donations. Many cardiac families have extremely high medical expenses and would not be able to take advantage of our services if we were to charge a fee for them. All donations are voluntary and are used by the organization to improve and enhance the quality of lives and information available for families with Congenital Heart Defects.

Almost everyone knows someone affected by CONGENITAL HEART DEFECTS and many of them think they are the only ones

Would this be you or someone you love?

You are not alone- we are here for you



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Providing support , information, and resources for families affected by congenital heart defects and children's acquired heart diseases

**SERVICES AVAILABLE THROUGH
KIDS WITH HEART NATIONAL ASSN FOR
CHILDREN'S HEART DISORDERS, INC**

- Parent Matching by congenital heart defect and/or related syndrome, even with prenatal diagnosis. Want to talk to another parent of a child with your child's diagnosis?
- Parent Matching by geographical location. Want to find another *heart family* in your area?
- Parent Matching to an adult with a similar congenital heart defect.
- Resources including books on congenital heart defects, some not available anywhere else as well as online support groups, etc.
- Nationwide Database of local support groups looking for a in-person support group in your area, we may have one listed for you.
- Toll free number allows families to stay connected from hospitals, home, anywhere they need to
- Bereavement Services. Unfortunately, a very necessary support area when dealing with congenital heart defects, our Bereavement Services are one of a kind. We have a complimentary Bereavement Packet as well as an online support group for anyone who has lost someone as a result of their heart defects.
- Parent Meetings Informal discussion meetings where parents may benefit from each other's experiences. Meetings are held in the NE WI area.
- Family Activities Holiday Party, Hayride, etc. throughout the year. These are important for the "heart" children themselves, siblings and parents, as well. Knowing they are not the only ones enduring these traumatic experiences. Also, they all benefit from seeing other kids who have been through what they may have to face yet. These are hosted in Northeast WI but anyone is welcome.
- Care Packages Many families must travel out of town for their child to have heart surgery- Green Bay does not have any children's heart facilities. The care package consists of snacks & juices that can be kept in the child's room at the hospital to help defray the cost of going out of town for surgery, a gift for the heart child- something that can be used while connected to machines, and small gifts such as coloring books, colors, etc for the other children in the family who are left behind with relatives or friends.

To request services for yourself or someone else, please call 1-800-538-5390 or visit us at www.kidswithheart.org



**Feb 14th, 2000
first ever Congenital Heart Defects Awareness Day**

In honor of this historical event, this ribbon pin was designed as a ribbon by Gabrielle Harlow from Maryland, in conjunction with Kids With Heart NACHD. This design was later modified by Michelle Rintamaki (Kids With Heart National Assn for Children's Heart Disorders, Inc.) to bring attention to its connection to congenital heart defects. **This pin is available through**

**Kids With Heart National Association
for Children's Heart Disorders.**

**To order your pins, magnets, or other
Congenital Heart Defect Awareness items,
please visit our [CHD Awareness Store](http://www.kidswithheart.org) at
www.kidswithheart.org click on Awareness
or call or fax us at 1-800-538-5390**

Our goal for Awareness is for everyone to unite to accomplish this purpose. Therefore, if you wish to use this design, please contact us prior to using it.

Goals for CHD Awareness

- Promote public recognition of congenital heart defects as the #1 birth defect as well as the leading cause of death from a birth defect. (1999-March of Dimes)
- Offer hope and assistance to families affected by congenital heart defects cope with feelings including isolation, loneliness, fear and embarrassment.
- To increase funding for research, support, and education for families affected by congenital heart defects.
- Resolve issues adult congenital heart defect survivors are now struggling with, including, but not limited to, the inability to get health and/or life insurance and job issues related to their congenital heart defects, so that our children do not have to struggle with these same issues in the future.



Did You Know?

**The Facts about
Congenital Heart Defects**

- **Congenital Heart Defects are the Most Common Birth Defect-about 640,000 to 1.3 million American have a congenital heart defect. Approximately 35,000 babies are born each year with a heart defect (AHA)**
- **There are 38 individual heart defects and many syndromes comprised of specific defects together.**
- **Congenital Heart Defects are the leading cause of death from birth defects during the first year of life. **Nearly twice as many children die each year from congenital heart defects as die from all forms of childhood cancers combined.** In 2005, 192,000 life-years were lost before age 55 in the U.S. due to congenital heart defects. In 2004, hospital costs totaled \$2.6 Billion. (AHA)**
- **People born with congenital heart defects need to see a cardiologist trained in treating congenital heart defects all their lives. They should NEVER switch to "general cardiologist" (ACHA)**
- **The actual cause of congenital heart defects is not known**
- **It is a proven fact that the earlier CHD is detected and treated, it is more likely the affected child will survive and have less long term health complications. (March of Dimes)**
- **Although some babies will be diagnosed during gestation or at birth, sometimes the diagnosis is not made until days, weeks, months, or even years after. In some cases, CHD is not detected until adolescence or adulthood. (March of Dimes)**