

**BEST
CHILDREN'S
HOSPITALS**

USNews
WORLD REPORT
HONOR ROLL
2011-12

C H D A W A R E N E S S

**1 IN 120 BABIES IS BORN
WITH A HEART DEFECT.**

Give them hope.



Make an appointment: **267-426-9600**

Learn more: heart.chop.edu/hope

YouTube



As a family member or friend of a child with a congenital heart defect (CHD), or someone who cares about kids' health, you have an incredible voice: your own. Children born and living with heart defects are an incredible example of the power of great medical care and great research.

Each year approximately 1 million children are born with heart defects. We want the public to be more aware of their journeys — and how we can all help improve the lives of these children.

Engaging and educating the public is a crucial step toward improving access to care, increasing funding for scientific research and educational programs, and passing laws that will allow for crucial early diagnosis and treatment.

Get the message out — become a *CHD Champion* today!

**Ways you can get
involved and become
an advocate for
children with CHD.**

See tips on
following pages.

- Contact your local media — television, radio or newspaper.
- Use social media networks like Facebook to educate friends and family.
- Make a donation, organize a fundraiser or sponsor an event to support research or clinical care.
- Volunteer.
- Advocate for laws and funding for CHD at the local, state or federal level.

Help bring pediatric heart disease to the attention of others and inspire them to also make a difference. *Thank you.*

 **The Children's Hospital of Philadelphia[®]**



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Congenital Heart Defects: Get the facts

- Congenital heart defects (CHD) occur in the early stages of pregnancy, when the heart is forming.
- Congenital heart defects include abnormalities in the heart's structure, electrical system and other abnormalities.
- Congenital heart defects are the most common birth defect, affecting approximately 40,000 births in the United States each year.
- Approximately 1 out of every 120 babies is born each year with some type of congenital heart defect.
- Nearly one-third of birth defect-related deaths of infants are caused by congenital heart defects.
- Congenital heart defects are approximately 60 times more prevalent than childhood cancer.
- Approximately 1.4 million children and adults in the United States are alive today with congenital heart defects.
- Genetic or chromosomal abnormalities cause some heart defects. Other risk factors include maternal smoking (during pregnancy), maternal obesity, maternal diabetes and maternal infections such as rubella.
- Caring for children with CHD is a challenging and complex endeavor that causes emotional and financial stress for families, and requires many hospital resources.
- Children with CHD are often at lifelong risk for other medical problems and cognitive or developmental complications.

Sources: March of Dimes, American Heart Association, Centers for Disease Control and Prevention

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Advocate. Share your story with elected officials and the public to create change.

Have you ever wondered what you can do to help protect the health and safety of children with congenital heart defects (CHD), in your community and the wider world? Children have no vote. But they do have a voice — yours.

What is advocacy?

Legislative Advocacy: Advocacy means “to speak up.” Legislative advocacy is speaking up for another or championing a cause in order to change public policy. As citizens, we have the ability to change laws, including those that affect children. We can do this by voicing our concerns to our legislators — writing letters, making phone calls and/or speaking in front of committees.

Community Advocacy: This type of advocacy draws a community’s attention to important issues at a local level (such as neighborhoods, schools and healthcare facilities). Community advocacy works by gaining support from our fellow citizens and elected representatives to bring about change.

Advocacy can improve the lives of children with CHD by:

- Serving as the voice of children as decisions are made that impact their health and welfare
- Educating the public and elected officials about issues important to children with CHD and their families
- Helping policymakers develop viable solutions to problems
- Banding together for the good of the cause

How to find your legislator

The following websites can help you identify your legislators:

- Pennsylvania: www.legis.state.pa.us
- New Jersey: www.njleg.state.nj.us
- Delaware: www.legis.state.de.us
- To learn the names of your two U.S. Senators and one U.S. Representative, go to www.senate.gov, and www.house.gov. Use the search functions “Find Your Senators” and “Find Your Representative.”

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Contacting your legislator

When contacting legislators by phone:

- Identify yourself by name and home address.
- Identify the bill you wish to talk about, by name and number if possible.
- Briefly state your position and how you wish your legislator to vote.
- Ask for your legislator's stance on the bill or issue and ask for a commitment to vote for your position.
- If your legislator needs additional information, gather support information and get it to your legislator as soon as possible.
- If the legislator is away from the office, leave a message or talk to an aide.

When contacting a legislator by letter, fax or email:

- State your position clearly in the first paragraph by asking your legislator to do something specific, such as sponsoring a bill or voting for or against a specific measure.
- Personalize your communication by explaining, as clearly and passionately as you can, why this matters to you.
- Write briefly and refer to bills by name and number.
- Sign your letter with your name, home address and phone number so that your legislator knows if you are a constituent and can contact you.
- Send a thank you note.

Address your letter as follows:

When writing to a
U.S. senator or state senator

The Honorable Mary/John Doe
(mailing address here)

Dear Senator Doe:

When writing to a U.S. representative
or state representative/assemblyman

The Honorable Anne/James Jones
(mailing address here)

Dear Ms./Mr. Jones:

When writing to a governor

The Honorable Mary/John Doe
(mailing address here)

Dear Governor Doe:

The Office of Government Affairs & Community Relations supports the community and legislative goals of Children's Hospital. We work with other departments throughout the Hospital and with community groups and government officials. We also work with patient families.

For more information, call 267-426-6904 or visit www.chop.edu/govt_affairs.

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Support. Philanthropic support powers every lifesaving treatment and breakthrough discovery.

See below for ideas on the ways you can be our partner in making extraordinary advances that will save the lives of countless children. Visit us at giving.chop.edu/SupportCardiac today to learn more!.

Donate Online: Instantly make a secure credit card gift to a fund of your choice, specify a recurring monthly gift, or make a pledge. Any amount you can give makes a difference.

Leave a Legacy Gift: A variety of giving opportunities are available if you wish to make a lasting contribution to a legacy of care.

Join a Giving Society: Children's Hospital appreciates the generosity and loyalty of its donors with exclusive recognition societies at every giving level.

Partner with Us: Children's Hospital welcomes organizational and corporate sponsorships for community outreach and fundraising events.

Create a Fundraising Page: It's simple to customize a tribute page for an individual, occasion or event with your own words and images and share it with friends and family to raise funds for Children's Hospital.

Join TEAM CHOP: In a race? Then consider joining TEAM CHOP and help us to ensure that every child has the opportunity for a healthy childhood.

Mail in a Donation: The Children's Hospital of Philadelphia Foundation
Lockbox #1352 P.O. Box 8500
Philadelphia, PA 19178-1352

To learn more about the many ways you can provide vital support, contact Patrick Feeley, Associate Vice President, at 267-426-6483 or feeley@email.chop.edu.

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Tell your story. Send a press release to your local newspaper, television or radio station.

A press release with details of your child's experience can help get your local newspaper, radio or TV station interested in your story. News stories go a long way in raising awareness about congenital heart defects. Use the document below to customize your own press release. (Look on the websites of the news outlets to find out how to send it to them.)

BEGIN CUT AND PASTE HERE

Put your name here.

Put your phone number here.

Put your email address here.

If you are affiliated with a nonprofit group, put the organization name here.

Media Contact at The Children's Hospital of Philadelphia: Joey McCool Ryan 267-426-6070

or mccool@email.chop.edu

Local Congenital Heart Disease Champion Celebrates CHD Awareness Month

(Your name) Rallies Support for Congenital Heart Disease Awareness and Funding in Partnership with the Cardiac Center at The Children's Hospital of Philadelphia

February is CHD Awareness Month. *(Your name)* joins with the Cardiac Center at The Children's Hospital of Philadelphia to champion support for congenital heart disease funding and to celebrate CHD Awareness Month to raise awareness that children can have broken hearts too.

(Insert your story and motivation for participation here. This section should be two to three paragraphs at most, written in third person. It should also include a quote from you.)

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“The availability of funding is vital to development of new and better treatments for congenital heart disease, and to continue to find some of the causes of congenital heart disease,” says Robert Shaddy, M.D., chief of cardiology at The Children’s Hospital of Philadelphia. “CHD Awareness Month helps bring pediatric heart disease to the forefront to inspire those who can make a difference.”

Heart defects are the most common birth defect in children, affecting 1 in 120 children. Survival rates for children with complex heart defects have improved dramatically over the past few decades but early diagnosis and treatment can make the difference.

Childhood Heart Champion *(your name)* is hoping to make a difference by sharing *(his or her)* story with the *(your city or town)* community.

For more information about how you can make a difference, visit heart.chop.edu/hope.

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Join the cause. Customize an “op-ed” for your newspaper.

Opinion pieces (“op-eds”) in newspapers reach many people and are a great way to raise awareness. Use your story to customize the op-ed below. Fax or email it to your local newspaper. (Look on the paper’s website for information on how to send it.)

BEGIN CUT AND PASTE HERE

Put your name here.

Put your phone number here.

Put your email address here.

If you are affiliated with a nonprofit group, put the organization name here.

Heart Disease Affects Kids Too

As patients, survivors, doctors and families across the nation celebrate CHD Awareness Month, take a moment to consider this: heart defects are the most common birth defects, affecting 1 in 120 children. Prenatal diagnosis helps inform the family and clinician so that a plan can be made. However, today many children are still born without a diagnosis before birth. Delay in treatment can make the difference between survival and demise. Brothers and sisters, sons and daughters, classmates and best friends — these are some of the most important reasons why congenital heart disease awareness and research needs to become a higher priority.

(Include your personal story here. This section should be two or three paragraphs at most.)

If the National Institutes of Health quadrupled the amount of research money it devotes to pediatric diseases, we might be able to cure the thousands of children who suffer from heart defects. In fact, someday we might even be able to prevent these devastating conditions. Funding pediatric research is a powerful way to make a difference for children and families everywhere.

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Pediatric cardiologists and researchers have already proven that they can make incredible, life-changing discoveries when given adequate resources. Over the past few decades, their work has led to a vast improvement in the survival rates for children with heart defects like hypoplastic left heart syndrome and transposition of the great arteries and improved life for children waiting for heart transplants. With more funding, researchers could find ways to minimize the long-term side effects that affect survivors' quality of life. They could develop new treatments and find cures. They could do so much more.

You don't have to be a scientist or a doctor to help make this happen. Write or call your U.S. senators and congressman and let them know why keeping kids' hearts in mind is important to you. Tell your story and remind them they can help by supporting the National Institutes of Health and the pediatric research it funds.

Join the cause today. Help cure childhood heart disease.

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Persuade others. Write your own “op-ed” for your newspaper.

Newspapers often publish opinion pieces (“op-eds”) by people in their community who are passionate about a cause. How about writing about how a congenital heart defect affected your family? Here are some tips for writing an op-ed likely to be published.

Write your own op-ed

If you'd like to write an op-ed from scratch, here are a few tips to help you get started.

- **Keep it short:** 500 to 700 words is good.
- **Keep it simple:** Use simple words and short sentences, and make your argument up front, in the very first paragraph. Avoid jargon and overly technical language.
- **Make it relevant:** Newspapers will be more likely to publish your op-ed if it relates to something that's currently in the news.
- **Add a call to action:** Tell readers what actions you want them to take. For example: “Elected officials should vote to increase funding for children with heart disease.” “Write to your legislator to show your support for childhood heart disease research.”
- **Use statistics:** Personalize your letter with facts and statistics about childhood heart disease.
- **Tell your story:** Personal stories are powerful. If you or someone you know has been affected by childhood heart disease, write about your experience.
- **Proofread it first:** Proofread your op-ed carefully before submitting it. Ask a friend or family member to proofread it too.
- **Include contact information:** Provide your name, email address and phone number.
- **Follow submission guidelines:** Op-ed submission guidelines can usually be found on the op-ed page of your newspaper or on the paper's website.

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