

# Congenital Heart Defects Resources

Explore these resources to find information, products, services and support for children with congenital heart defects and their families.

## Cardiology Services

- Congenital Heart Information Network (C.H.I.N.) [tchin.org](http://tchin.org)
- It's My Heart [www.itsmyheart.org](http://www.itsmyheart.org)
- Kids with Heart National Association for Children's Heart Disorders [kidswithheart.org](http://kidswithheart.org)

## General Information

- American Heart Association (AHA) [www.heart.org](http://www.heart.org)
- Centers for Disease Control and Prevention (CDC) [www.cdc.gov](http://www.cdc.gov)
- Mayo Clinic [www.mayoclinic.com](http://www.mayoclinic.com)
- National Birth Defects Prevention Study (NBDPS) [www.nbdps.org](http://www.nbdps.org)
- National Heart, Lung and Blood Institute (NIH) [www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)

## Parent Resources

### Advocacy: Awareness & support

- Congenital Heart Information Network (C.H.I.N.) [tchin.org](http://tchin.org)
- It's My Heart [www.itsmyheart.org](http://www.itsmyheart.org)
- Little Hearts [www.littlehearts.org](http://www.littlehearts.org)
- Mended Little Hearts [www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)

### Book reviews & book store

- Congenital Heart Information Network (C.H.I.N.) [tchin.org](http://tchin.org)
- It's My Heart [www.itsmyheart.org](http://www.itsmyheart.org)
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### Brochures (free of charge)

- American Heart Association (AHA) [www.heart.org](http://www.heart.org)



### Care packages: Deliver gifts & supplies during a child's hospital stay

- Mended Little Hearts [www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)
- Saving Little Hearts [www.savinglittlehearts.com](http://www.savinglittlehearts.com)

### Custom capes: Kids design and wear these during doctor visits & hospital stays

- Heart Heroes [www.heartherocapes.com](http://www.heartherocapes.com)

### Medical transport services: Rides for kids requiring specialized treatment

- Kids with Heart National Association for Children's Heart Disorders [kidswithheart.org](http://kidswithheart.org)

### Paying for medical care: Financial assistance, health insurance, income assistance & foundations

- NY State of Health: The Official Health Plan Marketplace <https://nystateofhealth.ny.gov>
- Congenital Heart Information Network (C.H.I.N.) [tchin.org](http://tchin.org)
- Hope for Hearts Foundation [hopeforheartsfoundation.org](http://hopeforheartsfoundation.org)
- NYS Department of Health Resource Directory for Children and Young Adults with Special Health Care Needs [www.health.ny.gov/publications/0548.pdf](http://www.health.ny.gov/publications/0548.pdf)



**Research matching: Connect with child research studies on medicines & treatment for congenital heart defects**

- **Bench to Bassinet** [www.benchtobassinet.org](http://www.benchtobassinet.org)
- **Pediatric Heart Network**  
[www.pediatricheartnetwork.com](http://www.pediatricheartnetwork.com)
- **Research Match** [www.researchmatch.org](http://www.researchmatch.org)

**Transplant resources: Learn about heart transplants & addressing children's needs through this process**

- **Children's Organ Transplant Association**  
[www.cota.org](http://www.cota.org)
- **Congenital Heart Information Network (C.H.I.N.)** [tchin.org](http://tchin.org)
- **Kids with Heart National Association for Children's Heart Disorders** [kidswithheart.org](http://kidswithheart.org)
- **Transplant Living (pediatric)**  
[www.transplantliving.org](http://www.transplantliving.org)

**Connect with Others**

**Family events & camps: Destinations for kids with congenital heart defects**

- **Congenital Heart Information Network (C.H.I.N.)** [tchin.org](http://tchin.org)
- **It's My Heart** [www.itsmyheart.org](http://www.itsmyheart.org)
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- **Little Hearts** [www.littlehearts.org](http://www.littlehearts.org)

**Local support groups: Education & networking resources**

- **Children's Heart Fund (Mount Sinai)**  
[www.childrensheartfund.net](http://www.childrensheartfund.net)
- **Mend-A-Heart Support Group (NYU Medical Center)** [pediatric-cardiac.med.nyu.edu](http://pediatric-cardiac.med.nyu.edu)
- **Mended Little Hearts (Buffalo, Rochester, Syracuse, Binghamton, and Lynbrook)**  
[www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)

**Membership organizations: Connect with other families, get information & learn about research**

- **Congenital Heart Information Network (C.H.I.N.)** [tchin.org](http://tchin.org)
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- **Mended Little Hearts**  
[www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)

**Online chats & networking: Connect with other parents across the country.**

- **Congenital Heart Information Network (C.H.I.N.)** [tchin.org](http://tchin.org)
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- **Little Hearts** [www.littlehearts.org](http://www.littlehearts.org)
- **Mended Little Hearts**  
[www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)

**Parent matching: Get to know others with kids with congenital heart defects**

- **It's My Heart** [www.itsmyheart.org](http://www.itsmyheart.org)
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- **Little Hearts** [www.littlehearts.org](http://www.littlehearts.org)
- **Mended Little Hearts**  
[www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)
- **Parent to Parent of New York State**  
[parenttoparentnys.org](http://parenttoparentnys.org)
- **Saving Little Hearts**  
[www.savinglittlehearts.com](http://www.savinglittlehearts.com)

**Stories & pictures of families who have kids with congenital heart defects**

- **Congenital Heart Information Network (C.H.I.N.)** [tchin.org](http://tchin.org)
- **It's My Heart** [www.itsmyheart.org](http://www.itsmyheart.org)
- **Little Hearts** [www.littlehearts.org](http://www.littlehearts.org)
- **Mended Little Heart**  
[www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)

**Contact Us**

**NY State Department of Health**  
Congenital Malformations Registry  
Center for Environmental Health  
Bureau of Environmental &  
Occupational Epidemiology  
Empire State Plaza-Corning Tower, Room 1203  
Albany, New York 12237  
(888) 296-8192  
[www.health.ny.gov/diseases/congenital\\_malformations/cmhome.htm](http://www.health.ny.gov/diseases/congenital_malformations/cmhome.htm)