



Helpful resources for families living with heart issues

Websites

- [Heart Center Educational Resources](#)
- [Adult Congenital Heart Association](#)
- [CASAhearts – Cardiac Arrest Survivor Alliance](#)
- [Children's Cardiomyopathy Foundation](#)
- [Heart Rhythm Society \(HRS\)](#)
- [Arrhythmogenic Right Ventricular Dysplasia/Cardiomyopathy \(ARVD/C\) Program| Johns Hopkins Heart and Vascular Institute](#)
- [My Life In Red](#)
- [National Institute of Health](#)
- [Parent Heart Watch](#)
- [Social Workers Help Starts Here](#)
- [Sudden Arrhythmia Death Syndromes Foundation \(SADS\)](#)
- [Sudden Cardiac Arrest Foundation](#)
- [Mayo Clinic](#)

Facebook groups

- [Mended Little Hearts Fort Worth](#) – private group; request to be added
- [Hope for ARVD](#) – public group
- [Young Hearts with ICDs](#) – private group; request to be added

Books

- *One Beat at a Time - Living with Sudden Cardiac Death* by Matthew D. Noble
- *Understanding Your Pacemaker or Defibrillator: What Patients and Families Need to Know* by Matthew D. Noble, Rebecca Fallon and David L. Hayes
- *ICD Connection: Living with an Implantable Cardioverter Defibrillator: A Collection of Patient and Family Stories* by Helen McFarland, RN
- *The Heart of a Child: What Families Need to Know about Heart Disorders in Children* by Catherine A. Neill, M.D., Edward B. Clark, M.D., and Carleen Clark, RN
- *Heart – Kids Discover* (volume 6, issue 10, December 1996) by Stella Sands
- *A Night without Stars* by James Howe
- *Jeff's New Pacemaker* by Jane Cullen
- *Heart Defects in Children: What Every Parent Should Know* by Cheryl J. Wild

Videos

- [Cook Children's - How to save a life using an AED and hands only CPR](#)
- [CPR in Adults](#)
- [CPR in Children](#)

- [CPR in Infants](#)
- [Take 20 for life hands only CPR](#)
- [Espanol hands only CPR](#)
- [How to use an AED](#)
- [How To Use An AED: Training for Every Age](#)

Camps

There are many camps for children with heart issues in the United States. Most offer family retreats and educational seminars.

Camp Odayin

Minnesota (various locations)

[Website](#)

info@campodayin.org

651-351-9185 phone

Camp Del Corazon California – Catalina Island

North Hollywood, California

[Website](#)

info@campdelcorazon.org

818-754-0312 phone

Camp Taylor

Modesto, California

[Website](#)

camp@kidsheartcamp.org

209-545-3853 phone

Camp Moss – kids living with heart disease

Affiliated with Cook Children's and Dallas Children's

Camp Jon Marc in Meridian, Texas

[Website](#)

laura.chalk@cookchildrens.org

682-885-4720 phone

Camp Sol

Affiliated with Cook Children's and Dallas Children's

Meridian, Texas

[Website](#)

lisa.jones@childrens.com

214-456-2870 phone

Open Hearts Camp

Great Barrington, Massachusetts

[Website](#)

hearts@openheartscamp.org

413-446-7000 phone

Hope with Heart

Waldwick, New Jersey

[Website](#)

201-264-6260 phone

Camp Rhythm

St. Louis, Missouri

[Website](#)

camprhythm@bjc.org

314-454-6000 phone

Camp Joyful Hearts

Clarksville, Ohio

[Website](#)

heartcamp@cchmc.org

Camp Brave Heart

Affiliated with Children's Healthcare of Atlanta

Rutledge, Georgia

[Website](#)

campbraveheart@choa.org

404-785-6735 phone

Camp Bon Coeur

Ponchatoula, Louisiana

[Website](#)

337-233-8437 phone

Camp Meridian

Tuftonboro, New Hampshire

[Website](#)

info@campmeridian.org

603-740-3254 phone