

# **ACTION (Advanced Cardiac Therapies Improving Outcomes Network), an international collaborative network for improving outcome of children with heart failure**

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## **BACKGROUND**

ACTION (Advanced Cardiac Therapies Improving Outcomes Network) consists of clinicians, researchers, parents, and patients from across a wide variety of medical institutions. The goal of the network is to improve critical outcomes for children with heart failure by uniting providers and families, sharing data and outcomes transparently, improving education, and standardizing best practices. The network consists of 57 national and 7 international institutions. Individual care centers do not have enough children with heart failure to achieve appropriate sample sizes for research or quality improvement activities, making partnerships between multiple centers necessary.

## **OBJECTIVE**

To introduce the ACTION network and involve relevant departments and clinicians at St. Christopher's Hospital for Children who care for patients with heart failure.

## **METHODS**

1. Complete the onboarding of St. Christopher's Hospital for Children as part of the ACTION network.
2. Build teams that can participate in different subcommittees and projects which will involve clinicians from various specialties including Pediatric Cardiology, CT Surgery, Anesthesiology and Pediatric Critical Care.
3. Involve patients' families, recruit to ongoing trials, promote advocacy, and utilize clinical educational tools.
4. Participate in the network research and QI projects, advance academic work, and collaborate in publications.

## **RESULTS**

Since its establishment in 2017, the ACTION collaborative network has grown across the US and abroad. The network outcomes include development of harmonization protocols and educational tools for patients, families, and caregivers. The network collaboration led to the publication of multiple manuscripts exploring multi-institutional outcomes and clinical care guidelines. Quality improvement projects are ongoing and new projects are emerging. The network online communication tools serve as robust resource for clinical discussions, brainstorming and innovation. The network organizational structure allows clinicians to focus on different aspects of pediatric heart failure including ventricular assist devices and mechanical support, medical management of heart failure, neuromuscular disorders, cardiac fitness, heart transplantation, adult congenital heart disease, anesthesia, and critical care management.

## **CONCLUSION**

Joining the ACTION network will open an array of opportunities to improve the care of pediatric patients with heart failure at St. Christopher's Hospital for Children, advance research, and collaborate with leading national and international institutions.

## **ACKNOWLEDGEMENTS**

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- SCHC Office of Resketch Support and Sponsored Programs
- ACTION Network

<https://www.actionlearningnetwork.org>



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# Mission and Highlights

action

## Our Collaborative

### Mission

ACTION will improve critical outcomes for children and adult congenital heart disease patients with heart failure by developing an international collaborative learning health system that unites all key stakeholders (patients, families, clinicians, researchers and industry).



### Key Values



### Improving Patient Outcomes



#### Impact to Care Delivery

- ▼ Decrease adverse event rates
- ▼ Prepare patients for transplant
- ▼ Improve donor organ utilization
- ▼ Optimize team communication
- ▼ Advance heart failure medicine therapy
- ▼ Engage patients to personalize care via self-reported surveys

### Improving Network Outcomes



#### Investment in Resources & Capabilities

- ▼ Share provider experiences & resources
- ▼ Expand education materials
- ▼ Data sources & data linkage to decrease burden
- ▼ Build a collaborative network with key stakeholders
- ▼ Expand use of registry data to include prospective trials

## Key Highlights

of the Advanced Cardiac Therapies Improving Outcomes Network include:

### Network Growth

- ▼ 50 pediatric centers participating (*See Appendix A*)
- ▼ 5 industry partners
- ▼ >30 parents and patients
- ▼ Expanding scope from VAD patients to all children with heart failure

### Quality Improvement

Active QI projects include:

- ▼ Stroke Reduction
- ▼ Increasing rates of VAD patient discharges
- ▼ Improving quality of telehealth visits
- ▼ Decreasing heart failure hospitalization length of stay
- ▼ Improving timeliness for Fontan referral to advanced care

### Data Collection

- ▼ Use of real world data for FDA approval of a device for pediatrics
- ▼ Data adjudicated quarterly for accurate & precise data
- ▼ 465 patients enrolled in ACTION registry

### Advocacy/Awareness

- ▼ All projects have a Family in ACTION member embedded in the work
- ▼ Patient reported outcomes have been successfully tested in 6 centers
- ▼ Increased educational opportunities including webinar series, research highlights webpage, and increased social media presence

### Network Collaboration

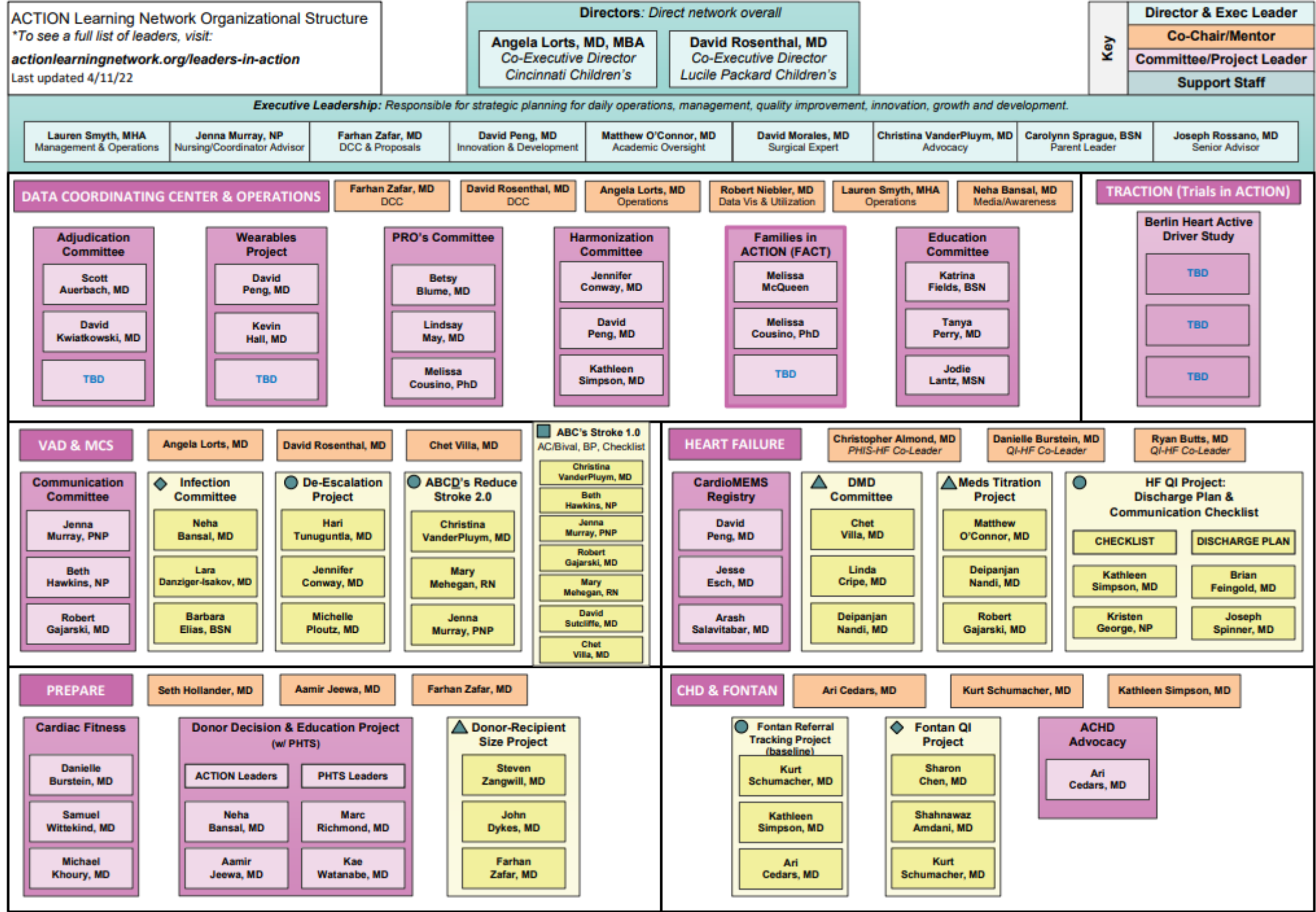
- ▼ Continue to collaborating with Cardiac Networks United
- ▼ Two projects with PHTS
- ▼ Linking data to PHIS and UNOS to decrease data entry



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# Organizational Structure



# Research Projects

## 7.0 Duchenne's Muscular Dystrophy Project (Baseline data collection)

Project Charter – Shared with the network in April 2021:



A. General Information	
<b>Project Title &amp; Project #:</b>	Improving Symptom Free Survival for Patients with DMD
<b>Department/Division/Team:</b>	<b>ACTION Network</b>
<b>Population:</b>	DMD patients with LVEF $\leq$ 45%
<b>Brief Project Description (AIM):</b>	The goal is to increase the number of patients receiving guideline directed medical therapy (GDMT) and timely consideration of advanced therapies.
<b>Measures:</b>	To increase the % of DMD patients receiving GDMT (TBD)
<b>Prepared By:</b>	Chet Villa, MD
<b>Date:</b>	Began Project Design: 1/1/2021 Project Roll-Out: 4/15/2021
B. Project Background:	
<p>Duchenne muscular dystrophy (DMD) leads to fibrofatty replacement of skeletal and cardiac muscle. This translates into progressive skeletal muscle weakness, respiratory <u>insufficiency</u> and cardiomyopathy. The earliest manifestations of cardiac disease are increasingly well understood through a multifaceted approach of biomarker evaluation, strain imaging, cardiac magnetic resonance imaging (<u>cMRI</u>), and rhythm monitoring. However, medical therapy prior to the onset of severe heart failure remains inconsistently applied, while the number of pharmacologic therapies for dilated cardiomyopathy is growing rapidly. The long term survival of men with DMD is also increasing, leading to a growing number of people living with severe, ventricular dysfunction. This has presented clinicians and families with the necessity of making significant decisions regarding cardiac care (including advanced therapies such as implantable cardioverter-defibrillators (ICDs), ventricular assist devices (VADs) and heart transplantation while practice is rapidly <u>evolving</u> and therapeutic benefit is not yet defined.</p> <p>This project seeks to understand current heart failure outcomes in DMD. We will then use a data driven approach to optimize the number of patients receiving GDMT (or consensus driven therapy for specific medical/advanced therapies if applicable) and those receiving a timely evaluation/discussion of advanced therapies.</p>	



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# QI Projects

Name	Project Status	Launch Date
ABC's Stroke 1.0 (Bival, BP, & Comm Checklist)	Active/Sustain	December 2018
ABCD's Stroke 2.0 (ABC's revamp + Discussion & Data)	Active	May 2021
Heart Failure QI (Comm Checklist & Discharge Plan)	Active	January 2021
De-escalation QI (Flight Plan & Journey Map)	Active	February 2022
DMD (baseline data collection)	Active	April 2021
Fontan Referral (baseline data collection active, next phase QI design)	Active	July 2020
Donor-Recipient Size Match (TCV measurement variability)	Design/Pilot	January 2021
Donor Decision Forum w/ PHTS (discussion of transplant donor cases w/ voting/learning)	Active	June 2020
Patient Reported Outcomes via Tonic	Active	July 2021
Education (Patient & Family) via myactioneducation.org	Active	October 2020
Education (Provider) via myactioneducation.org	Active	January 2021
CardioMEMS (baseline data collection)	Active	August 2021
Apple/ Wearables Project (wearable data collection)	Design/Pilot	April 2022
Meds Titration via Telehealth (baseline data collection)	Design/Pilot	March 2022
Berlin Heart Active Driver Study (first study of TRACTION)	Design	July 2022
Harmonization of Protocols & Guidelines	Active	January 2018
Communication Projects (iDecide, Hand-off Tool)	Design	March 2022
Infection Reduction (review baseline data and design for QI)	Design	May 2022
Cardiac Fitness (exercise/rehab protocol)	Design	June 2022



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# Publications

## Publications

- ▼ Villa CR, VanderPluym CJ; ACTION Investigators\*. ABCs of Stroke Prevention: Improving Stroke Outcomes in Children Supported With a Ventricular Assist Device in a Quality Improvement Network. *Circ Cardiovasc Qual Outcomes*. 2020 Dec;13(12):e006663.
- ▼ Bearl DW, Feingold B, Lorts A, Rosenthal D, Zafar F, Conway J, Elias B, Tunuguntla H, Thurm C, Amdani S, Jaworski N, Godown J. Discharge and Readmissions After Ventricular Assist Device Placement in the US Pediatric Hospitals: A Collaboration in ACTION. *ASAIO J*. 2020 Nov 12.
- ▼ Neha Bansal, Danielle S. Burstein, Angela Lorts, Lauren Smyth, David N. Rosenthal, David M. Peng, Heart failure in children: Priorities and approach of the ACTION collaborative, *Progress in Pediatric Cardiology*, Volume 59, 2020.
- ▼ Hollander SA, Nandi D, Bansal N, Godown J, Zafar F, Rosenthal DN, Lorts A, Jeewa A; ACTION Network. A coordinated approach to improving pediatric heart transplant waitlist outcomes: A summary of the ACTION November 2019 waitlist outcomes committee meeting. *Pediatr Transplant*. 2020 Sep 28.
- ▼ Lorts A, Smyth L, Gajarski RJ, et al. The Creation of a Pediatric Health Care Learning Network: The ACTION Quality Improvement Collaborative. *ASAIO J*. 2020;66(4):441-446.
- ▼ O'Connor MJ, Lorts A, Davies RR, et al. Early experience with the HeartMate 3 continuous-flow ventricular assist device in pediatric patients and patients with congenital heart disease: A multicenter registry analysis. *J Heart Lung Transplant*. 2020;39(6):573-579.

## ORIGINAL ARTICLE



## Multisystem Inflammatory Syndrome Associated with COVID-19 Anti-thrombosis Guideline of Care for Children by Action

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### Abstract

With growing number of pediatric cases of COVID-19, a unique hyper-inflammatory syndrome, linked to SARS-CoV-2 infection, has emerged in children referred to as multisystem inflammatory syndrome in children (MIS-C). This Kawasaki Disease (KD)-like illness has been described across the world. This syndrome shares features of KD, toxic shock syndrome, and macrophage activation syndrome and is associated with significantly elevated inflammatory markers. Everyday there are new data emerging improving the care of these patients. The Advanced Cardiac Therapies Improving Outcomes Network (ACTION) is a collaborative network designed to improve the outcomes of pediatric patients with end-stage heart failure and involves centers from across North America. The committee gathered information concerning COVID-19 anticoagulation practices at various centers and harmonized the data to formulate a set of recommendations.



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# Participating Hospitals

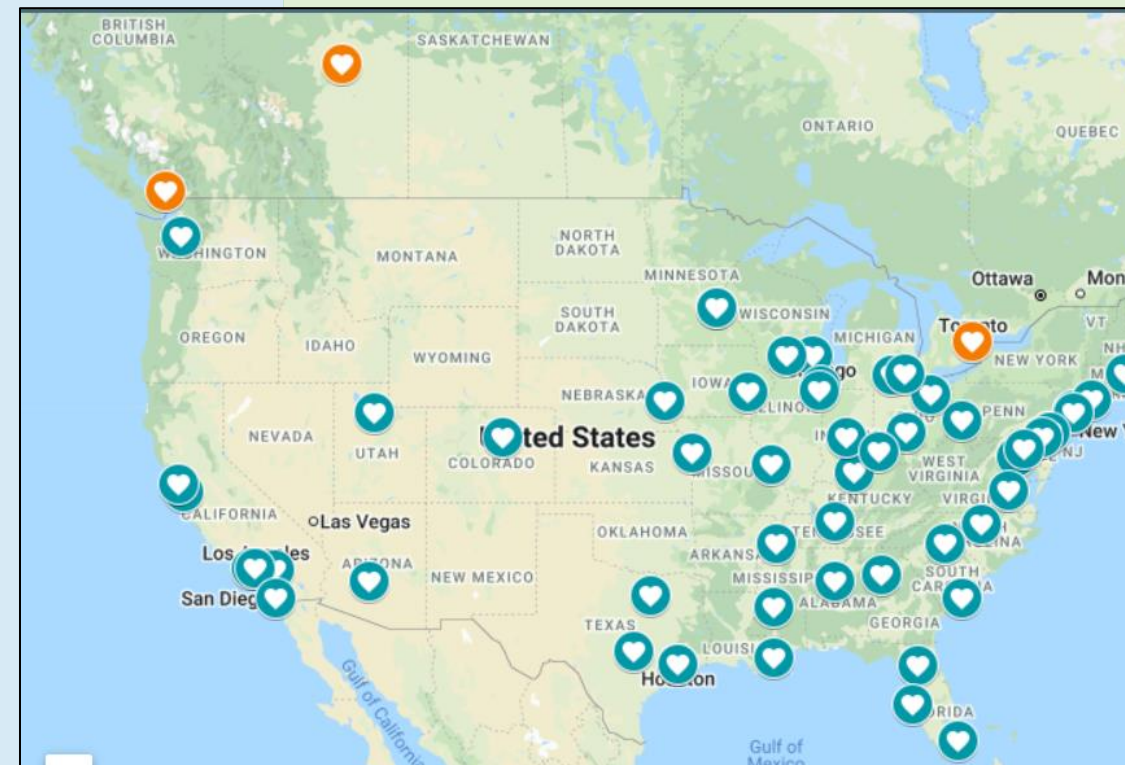
## Our Participating Sites

- ▼ Advocate Children's Hospital
- ▼ Boston Children's Hospital
- ▼ C.S. Mott Children's Hospital
- ▼ Children's Health Dallas
- ▼ Children's Healthcare of Atlanta
- ▼ Children's Heart Center at Mount Sinai Hospital
- ▼ Children's Hospital at Montefiore
- ▼ Children's Hospital Colorado
- ▼ Children's Hospital Los Angeles
- ▼ Children's Hospital of Michigan
- ▼ Children's Hospital of Philadelphia
- ▼ Children's Hospital of Pittsburgh
- ▼ Children's Hospital of Richmond at VCU
- ▼ Children's Hospital of Wisconsin
- ▼ Children's Mercy Kansas City
- ▼ Children's Minnesota
- ▼ Children's National Medical Center
- ▼ Children's of Alabama
- ▼ Cincinnati Children's Hospital Medical Center
- ▼ Cleveland Clinic Children's Hospital
- ▼ Dell Children's Medical Center of Central Texas
- ▼ Duke Children's Hospital
- ▼ Hassenfeld Children's Hospital at NYU Langone
- ▼ Joe DiMaggio Children's Hospital
- ▼ Le Bonheur Children's Hospital
- ▼ Levine Children's Hospital
- ▼ Loma Linda University Children's Hospital
- ▼ Lucile Packard Children's Hospital
- ▼ Lurie Children's Hospital of Chicago
- ▼ Monroe Carell Jr. Children's Hospital
- ▼ Morgan Stanley Children's Hospital of New York Presbyterian
- ▼ MUSC Children's Health
- ▼ Nationwide Children's Hospital
- ▼ Norton Children's Hospital
- ▼ Ochsner Hospital for Children
- ▼ Phoenix Children's Hospital
- ▼ Primary Children's Hospital
- ▼ Rady Children's Hospital
- ▼ Riley Hospital for Children
- ▼ Seattle Children's Hospital
- ▼ St. Louis Children's Hospital
- ▼ Stollery Children's Hospital
- ▼ Texas Children's Hospital
- ▼ The Hospital for Sick Children
- ▼ UCLA Mattel Children's Hospital
- ▼ UCSF Benioff Children's Hospital
- ▼ UF Health Shands Children's Hospital
- ▼ University of Iowa Stead Family Children's Hospital
- ▼ University of Minnesota Masonic Children's Hospital
- ▼ Yale New Haven Children's Hospital

## International Sites

- ▼ The Royal Children's Hospital, *Melbourne, Australia*
- ▼ Newcastle upon Tyne Hospitals NHS Foundation Trust, *United Kingdom*
- ▼ Great Ormond Street Hospital for Children, *United Kingdom*
- ▼ National Heart Institute (Institut Jantung Negara, Kuala Lumpur) *Malaysia*
- ▼ British Columbia Children's Hospital, *ancouver, British Columbia*
- ▼ Heart Institute (InCor) University of São Paulo Medical School, *São Paulo, Brazil*
- ▼ Bambino Gesù Children Hospital, *Rome, Italy*

For more information or to get involved email:  
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