

2020 Highlights Report

Our Mission

is to 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 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



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.

[Links to all publications on our Research Highlights webpage](#)

Leaders & Network Organization

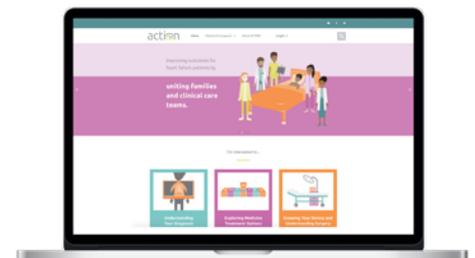
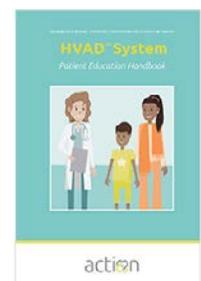
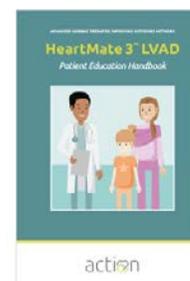
- ♥ >50 Leaders
- ♥ 8 New Committees/Projects: *Fellows Stakeholder Group, Infection Prevention Committee, Donor Decision Forum w/ PHTS, Wearables/Apple Watch Project, Telehealth QI Project w/ PHTS, CardioMEMS Registry, Fontan Referral Tracking Project*

Education

- ♥ Launched [MyACTIONEducation.org](#) which includes videos, modules, infographics, and other materials for patients/families to learn about heart failure and VAD's.
- ♥ Released patient handbooks for the HeartMate 3™ LVAD and the HVAD™ System

Harmonized Protocols

- ♥ 8 New Harmonized Protocols for centers to test and adapt



Follow us on Twitter [@Action4HF](#) to see all our recent activity and updates.

Appendix A

to date as of January 20, 2021

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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