2019 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
- 44 pediatric centers participating (See Appendix A)
- 4 industry partners
- >30 parents and patients
- Broadening activities to improving care for children waiting for heart transplant

Quality Improvement
27 centers participated in QI initiatives
- All Berlin Heart patients on ACTION Bivalirudin Protocol
- All CF-VAD patients have blood pressures measured using standardized protocol
- All devices, all patients part of new Rounding Checklist
- Designed & began testing interventions for the Discharge and De-escalation project
- Testing patient journey map and team flight plan to improve VAD post-op care & CF-VAD patient discharge rates
See attached infographics

Data Collection
- Data adjudicated quarterly for accurate & precise data
- Real-time data and data collection for FDA & trials
- Web-based electronic database updated & revised to ensure most impactful data is collected

Stroke rates are DOWN from 30% to 12% in Berlin patients at ACTION sites

VAD ACTION Flight Plan

See attached infographics

action

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Patient Advocacy/Awareness

- Families in ACTION (FACT) Advisory Council created & patients/families embedded in network initiatives
- Designing to collect Patient Reported Outcomes (PRO’s) across network, and developing an ACTION PRO questionnaire
- Social media & story sharing to build support and advocacy for patients & families

Network Collaboration

- Collaborating with Cardiac Networks United (including NPC-QIC, PAC3, PC4, & CNOC), PHTS, PHIS, & Pedimacs to decrease redundancy in data collection & share learnings

Publications

- 9 abstracts accepted for ISHLT 2020, Montreal
- ACTION White Paper accepted to ASAIO Journal
- Fontan VAD Physiology manuscript data collected, will complete writing in 2020
- ABC’s of Stroke Reduction submitted
- HeartMate 3 manuscript submitted

Leaders & Network Organization

- 50 Leaders
- New Committees: Waitlist Outcomes & Heart Failure committees

Education

- Patient/Family Education Bundle: videos, electronic education modules, video games, informational flyers, patient handbook

Harmonized Protocols

- 11 Harmonized Protocols for centers to test and adapt

Data Reporting

- Real-time learning & data getting to the bedside faster with interactive data reports

@ACTION4HF
Follow us on Twitter to see all our recent activity and updates in 2020

“It (ACTION) makes me feel good because everybody from around the world can get the same care.”

Brooklyn, ACTION Patient
Appendix A

to date as of January 31, 2020

Our Participating Sites

- 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 Philadelphia
- Children’s Hospital of Pittsburgh
- Children’s Hospital of Wisconsin
- Children’s Mercy Kansas City
- Children’s National Medical Center
- Children’s of Alabama
- Cincinnati Children’s Hospital
- Cleveland Clinic Children’s Hospital
- Dell Children’s Medical Center of Central Texas
- Duke Children’s Hospital
- 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
- 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 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
- National Heart Institute (Institut Jantung Negara, Kuala Lumpur), Malaysia

For more information or to get involved please email: info@actionlearningnetwork.org
Take ACTION: Active QI Initiatives

**ANTICOAGULATION**

**Initiative**
- Bivalirudin Standardization
- Simple Algorithm
- Standardized Blood Draws

**Population Effected**
Berlin Heart VAD patients

**Goals**
Trial the use of the Bivalirudin protocol 90% of the time to determine if it improves target range values.

**BLOOD PRESSURE**

**Initiative**
- Standardization of Blood Pressure Measurement
- Easy Reference Guide

**Population Effected**
Continuous Flow VAD patients

**Goals**
Improve use of the blood pressure measurement tool from 0–65% to determine if blood pressure is consistently measured.

**COMMUNICATION**

**Initiative**
- VAD Stroke Prevention Checklist for Rounds
- Improve Situational Awareness
- Improve Patient/Family Experience

**Population Effected**
All VAD patients

**Goals**
Complete stroke prevention checklist 5–7 days each week to improve communication between care team, patients and families.

**DISCHARGE**

**Initiative**
- Goal-setting VAD post-op flight plan for VAD & ICU teams
- Patient/family VAD education journey map

**Population Effected**
Continuous Flow VAD patients

**Goals**
Increase percent of patients who are discharged from 28% to 75% and decrease median time to discharge from 34 days to 30 days.
VAD Patient Journey

Use the marker to circle your place in the journey.

*All patients are unique and may not follow the path exactly as shown. Some steps will need to be determined by the care team and/or some may not apply.

1. VAD consult
2. Learn about VAD and meet the VAD team
3. VAD Surgery
4. Start blood thinning medicines and work toward goal level
5. Remove the breathing tube
6. Transfer ready: VAD settings and medicine levels stable*
7. Transition out of ICU to step down care*
8. Time to get stronger
9. Learn about VAD equipment
10. CPR training
11. Sterile dressing changes
12. Learn how to Doppler blood pressure*
13. Packing a VAD "go bag"
14. Learn your medicines
15. Pick up prescriptions and fill pill box
16. Caregivers demonstrate competencies
17. Practice VAD self-care and hygiene
18. Home assessment*
19. Excursions* (playground, cafeteria, etc.)
20. Home therapies and nursing arranged*
21. Local EMS/fire/utilities contacted to update info*
22. Follow-Up appointments scheduled (lab, rehab, clinic)*
23. Patient and family are ready*
24. Transition out of the hospital*
25. Life outside hospital*
26. Device training: getting ready for school/work*
27. Back to school/work*
28. Enjoy life as your journey continues

*All patients are unique and may not follow the path exactly as shown. Some steps will need to be determined by the care team and/or some may not apply.