

# Heart Failure Registry

## Summary



### Objectives

- Create a single repository for all ACTION Heart Function and Failure related projects
- Rapidly acquire and disseminate data related to use and outcomes of medications used in children and in adults with congenital heart disease for the treatment of heart failure symptoms and/or impaired heart function

### Inclusion

- Any patient admitted to the intensive care unit or floor unit for treatment of impaired systolic or diastolic heart function and/or symptoms of heart failure
- Heart Failure Definition: A clinical syndrome that results from any structural or functional impairment of ventricular filling or ejection. Cardinal symptoms include but are not limited to breathing difficulty, feeding intolerance, and decreased activity
- Exclusion Criteria: Patients with a dystrophinopathy being entered in the ACTION DMD Registry

## FAQs: Patient Inclusions + Exclusions

### Q. Is there an age restriction?

- **No**, there is no age cut-off for enrollment. We can decide at a later time to use specific age cut-offs when analyzing data.

### Q. Should we include patients with Fontan circulatory insufficiency?

- **Yes**, please include patients with Fontan circulatory insufficiency for whom you are using medications to help improve impaired diastolic or systolic dysfunction. Please pay attention to the Fontan phenotype specific questions on the Enrollment Form under Primary Cardiac Diagnosis.

### Q. Should we include patients who develop cardiac dysfunction after they have been admitted?

*ex: a patient who develops cardiac dysfunction while admitted for a different reason, such as for chemotherapy*

- **Yes**, you can include this patient. On the admission form, it will ask you to list either the (1) Admission Date, (2) Date of Diagnosis of Decreased Heart Function, and/or (3) Date of Heart Failure diagnosis in a patient already in the Hospital.

### Q. Should we include patients who have persistent cardiac dysfunction following surgery for congenital heart disease?

*ex: could not get off milrinone following 2V repair or BDG*

- **Yes**, you can include this patient. On the admission form, it will ask you to list either the Admission Date or Date of Diagnosis of Decreased Heart Function and/or Heart Failure in a Patient already in the Hospital. Please wait at least 30 days following surgery before deciding to enroll the patient.

### Q. Should we include ALL patients with post-operative cardiac dysfunction?

- **No**, please do not include patients who have temporary cardiac dysfunction following palliation/surgery for congenital heart disease. If a patient has persistent cardiac dysfunction 30 days after surgery and is being

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discharged home on medications being used specifically to help improve diastolic or systolic function (not used for high blood pressure or AV valve regurgitation), or undergoes placement of a VAD or undergoes heart transplant during the same hospitalization as surgery, then you can include this patient.

**Q. Should we include patients with pulmonary over circulation?**

*ex: unrepaired VSD*

- **No**, please do not include children with symptoms due to pulmonary over circulation.

**Q. Should we include patients with BMD or DMD?**

- **No**, please do not duplicate your efforts and include a patient with either BMD or DMD IF you are enrolling the same patient in the ACTION DMD registry. If you are not participating in the DMD registry, then feel free to include