Dear ACTION Centers and Leaders,

We are excited to announce the development of ACTION’s **Patient and Family Advisory Council**—**“Families in ACTION” (FACT).** This group of approximately 10-15 members will help to guide our quality improvement initiatives by sharing their lived experiences, contributing to intervention design and implementation, and raising awareness of our learning health system via social media and advocacy efforts. *Please note this is a larger commitment for patients and families than past parent initiatives.*

We are seeking your nominations for patients, parents, and caregivers to help launch this important council.

**WHO**

We are recruiting a diverse group of patients, parents and caregivers to comprise our council, especially in regards to demographics such as age of patient, mother and father representatives, heart disease/VAD course (pre/post VAD, device type, inpatient vs. home discharge, etc.), cultural/ethnic background, heart center, etc. Specifically, we are looking for council members who meet the following criteria:

* Patient (Ages 10 and Up) with Advanced Heart Disease and/or VAD Experience
* Parent and Caregiver of Pediatric Patient or Young Adult with Advanced Heart Disease or VAD Experience
* Receiving Care at an ACTION Center

**ROLES & RESPONSIBILITIES**

* FACT council members will serve a 2-year term with opportunity for renewal if interested.
  + A council member may leave the group at any time and due to any reason. If the member wishes to return to the council at a later date, the member request must be approved by the co-chairs and executive leadership.
* Participate in quarterly 60-minute FACT meetings via video/phone conferencing.
* Willingness to participate in ad-hoc FACT meetings if a meeting needs to occur before the next regularly scheduled quarterly meeting.
* Review and provide feedback on committee project proposals, educational materials, and intervention designs.
* Participate in surveys of patients, parents, and caregivers to inform priority needs and initiatives.
* Share the mission and work of ACTION via social media and within one’s center/networks.

**NOMINATE A PATIENT / CAREGIVER**

To nominate a patient, parent or caregiver, please send the following to Lauren Smyth at [Lauren.Smyth@cchmc.org](mailto:Lauren.Smyth@cchmc.org). **Please submit nominations by August 16, 2019**. Final council invitations will be determined by ACTION Provider-Patient Experience Co-Chairs, Melissa Cousino PhD and Melissa McQueen, and ACTION Executive Leadership to ensure a diverse group of representatives across our centers.

* Name of Patient or Caregiver:
* ACTION Center:
* Current Age of Patient:
* Patient Age at Implant (If Applicable):
* Caregiver Role (If Applicable):
* Primary Language:
* Race/Ethnicity:
* Contact Email:
* Cardiac Diagnosis:
* Device Type (If Applicable):
* Post VAD Outcome (If Applicable):
* Discharged Home on VAD (If Applicable):

Thank you for supporting this exciting initiative!

**Melissa Cousino, PhD & Melissa McQueen**

*On Behalf of ACTION Executive Leadership*