



SV-ONE SPRING 2026 VIRTUAL LEARNING SESSION

Voices United: Patients, Families, & Clinicians
Partnering to Drive Change

TEAM TIME WORKSHEET

The prompts below are designed to guide a discussion that begins with input from patients and family members and incorporates their perspectives into a concrete plan to strengthen patient and family engagement at your center.

Step I: Hearing from Patients and Family Members

1. In what ways are you currently involved in work at our center, if at all? (You may go around the room for verbal responses or invite participants to write responses on Post-it notes if the group is large.)
 2. Are there additional or new ways you would like to be involved in our center's work?
 3. What needs, priorities, or perspectives do you feel could be better addressed through increased patient and family involvement?
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Step II: Turning Input into Action

1. Based on what you've just heard, what new or expanded opportunities exist for patients and families to collaborate with your team? Please see the examples provided in the Engagement Ideas section on the next page.

2. What specific actions will your team take in the next 90 days to strengthen patient and family engagement?

3. Who will be responsible for each action?

4. How will you know whether these efforts are meaningful to patients and families?

Engagement Ideas: The following is a list of patient and family engagement programs and activities implemented by SV-ONE centers. It is intended to serve as a source of ideas for new ways to increase patient and family engagement at your center.

Co-Creation

- C1. Family members meet monthly with clinicians, program leaders, and staff to provide direct feedback on clinical practices, communication tools, and patient-facing resources. This includes patient/family interviews and committee participation.
- C2. Parents work with clinicians to develop new guidelines.
- C3. Clinicians collaborate with patients and parents as a multidisciplinary team, including nephrologists, nutritionists, social workers, cardiologists, pulmonologists, and exercise physiologists in a bi-monthly Fontan clinic.
- C4. Patients and family members collaborate on research proposals.

Networking

- N1. Graduated families are paired with new families for peer support.
- N2. Engage with community on social media.
- N3. Support groups are available for patients and families.
- N4. A Cardiac Care Unit Parent Welcome Guide was developed.
- N5. An inpatient rewards system allows patients to earn tokens to redeem for prizes.

Team Meetings

- T1. Parents attend our monthly team meetings.
- T2. Dedicated parent and family team time is included in SV-ONE Learning Sessions.
- T3. Families are involved in SV-ONE committees.

Feedback

- F1. Parents review a variety of materials and tools to provide feedback/suggest edits, such as new educational materials and an electronic home monitoring data collection system.
- F2. Parents are provided with surveys at the completion of their Interstage period.
- F3. Feedback sessions are held with a small number of families to gain insight and input.
- F4. Parent surveys are used to gather feedback on programs.

Advisory Group

- A1. Parent/provider advisory board: Meets monthly and works to improve patient & family care experience.
- A2. Cardiac Patient & Family Advisory Council: Parents and families provide feedback on cardiac-related topics and initiatives.
- A3. Heart Institute Patient & Family Advisory Council Meetings: Virtual and in-person forums for patient and family input across the Heart Institute.
- A4. Single Ventricle (SV) Parent Advisory Board: SV parents, patients, and center staff meet regularly and organize outreach.
- A5. SV-ONE Advisory Group: An SV-focused advisory group within an institutional Patient and Family Advisory Council to inform cardiology initiatives.
- A6. Parent advisory boards: Specialized parent boards, including a cardiac Interstage parent board for SV families and an infant mental health parent board.
- A7. Create a single ventricle patient/family network that provides guidance on projects and interventions.

Events

- E1. Family-focused events, including learning sessions, Q&A panels, and breakouts or small groups that encourage collaboration and input.
- E2. Regular social gatherings for families to get together and do something fun.
- E3. Family-oriented events run by various clinics, such as the Heart Center, the Stroke & Seizure Center, or the Cardio-Neurodevelopmental Center.
- E4. Encourage patients from our center to start joining the virtual or in-person Learning Sessions.
- E5. Heart walk
- E6. Annual patient/parent meeting aimed at patient education, networking among families for support, and improving care.
- E7. Invite families to speak and share their experiences at local educational conferences or hospital events.
- E8. Cardiac program hosted a regional conference for APPs on HLHS management from prenatal diagnosis through interstage. Four parents participated and provided a very impactful parent perspective.