

The Single Ventricle Journey:

A Guide for Parents and Families

CREATED BY

National Pediatric Cardiology Quality Improvement Collaborative
Fetal Learning Lab *with contributions from Sisters by Heart*

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This guide was created for families undergoing prenatal diagnosis of single ventricle anomalies. It is a collaborative effort by the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) Fetal Learning Lab.

Note to Practitioners/Centers

As a practitioner or center that cares for these patients, we would like to offer you this resource. Please share this guide with the families under your care as a comprehensive overview of single ventricle congenital heart defect diagnosis, treatment, and life-long management. This guide is meant to be used as an adjunct to your routine counseling practices and to supplement



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other resources that you may already use. It is not meant to supplant any existing materials from your program/center or replace the face-to-face time with the family that is so critically important.

We suggest this guide be presented to the family after the first counseling session or at a subsequent follow-up visit, depending on the parents' state of readiness to receive additional information. It is possible that families will be presenting to your centers at various states along the diagnosis and counseling pathway, such that some have already had multiple consultations, and others may be hearing the news for the very first time. When deemed ready, please present this guide to them and encourage them to read through it and develop questions which can be discussed at subsequent encounters with your care team.

This guide was created through a joint effort of an array of healthcare practitioners (MD, RN, RD, SW, etc.) and families of children with single ventricle congenital heart defects through our work with NPC-QIC and Sisters by Heart. It comprises the work of over 50 authors from 25 institutions across the US. The information provided goes well beyond the initial hospital stay and postoperative recovery such that it can continue to be used as a resource for families well past the neonatal period, as well as being an appropriate resource for families entering your care beyond the prenatal period. Our plan is to update and add chapters on an annual basis to keep the information current and relevant.

We hope this guide serves your families well in providing them the information and support needed to get through the difficult period of diagnosis and beyond.

SINCERELY,

The NPC-QIC Fetal Learning Lab Leaders

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