

Newborn Critical Care Center (NCCC) Clinical Guidelines

Collaborative Cardiac Care for Patients with *Complex* Congenital Heart Disease in the NCCC

PATIENTS WHO ENTER UNC PRENATALLY

Ideally, patients will enter through CMIH where the case will be reviewed in CMIH conference and consultation with 1) Neonatology, 2) Cardiology, 3) CT surgery, 4) Other sub-specialists will be performed, as deemed appropriate by the CMIH group.

The neonatologist, pediatric cardiologists, and/or pediatric CT surgeons performing the prenatal consults will clearly document their discussions and recommendations in the Mother's chart to be reviewed by the admitting Neonatologist.

If concern is raised by the fetal cardiologist that the patient has a constellation of findings in which cardiac surgery might not be offered at UNC, the patient will be presented at the next congenital heart program multidisciplinary meeting for discussion of the findings. Once a consensus is agreed upon, the findings will be presented to CMIH.

- A. If consensus among the congenital heart program is not to offer surgery at any time, and cardiac surgery is desired, then the recommendation will be to refer to another institution for delivery. Prenatal palliative care should become involved if not already instituted.
- B. If consensus among the congenital heart program is that surgery may not be indicated during the neonatal period, but might (not guaranteed) be offered at a later time based on the physiology and clinical course, then this will be presented to CMIH for discussion as to whether the patient should be delivered at UNC.

PATIENTS WHO ENTER UNC POSTNATALLY

Patients who have a postnatal diagnosis of congenital heart disease will be evaluated first by a neonatologist who will administer primary intensive care. When a cardiac lesion has been identified, consultation will occur with the pediatric cardiology team.

As appropriate, the pediatric cardiology MD will discuss the patient with the UNC Cardiac Team (including CT surgery, PCICU) and determine a plan for cardiac care. This plan will be communicated to the treating Neonatology Team. Both neonatology and cardiology will communicate the recommended treatment plan to the family.

Regarding patients with cardiac surgery in the immediate neonatal period

The TICKER system should be activated for coordination of care with PCICU

Regarding patients for whom cardiac surgery is NOT recommended

- **Parents are in agreement:**
 - Continued medical care by neonatology, with consultation by cardiology. The pediatric supportive care should be consulted.
- **Parents wish to pursue a second opinion:**
 - Second opinions will be sought at all other North Carolina based institutions as appropriate (ex: per Medicaid requirement), regional centers, or specialty centers based on lesion or patient specific characteristics. Family preferences will be a part of the decision process. The family will be informed that the process will take days to weeks to receive a formal answer from other institutions, and that ongoing care will continue at UNC. Pediatric supportive care consult should be considered while awaiting decisions from other centers. An ethics consult can also be considered.

A maximum of 4 total opinions will be sought at other centers based on parental desire. Payor related requirements (ie: need to consult NC-based institutions), should not detract from this maximum number. Pediatric Cardiology will be the primary facilitator for seeking second opinions, with Neonatology being the secondary point of communication to provide information about other organ systems/other aspects of the medical care. The Neonatology team will get consent to send the medical record. The cardiology team will provide Echocardiogram and/or cardiac catheterization images. NCCC discharge coordinators will provide H&P, current progress notes, other imaging, and other clinical documents as requested by outside hospital.

All decisions from outside institutions will be documented in the chart and communicated to the primary Neonatology team. Both cardiology and neonatology will inform the family of the findings.

If a center agrees to accept the patient for transfer, cardiology will continue to facilitate conversations with the accepting center and solicit advice as appropriate. Pre-transfer care will be administered by the UNC neonatology and the pediatric cardiology groups. Advice from outside opinions will be considered, but UNC MDs will remain the primary care providers until transfer.