**NOTE 5**

**PATIENT 1002**

**DATE: 4/29/20**

**Patient Summary**

Patient (triplet A) is a 2 month old 27 4/7 wks GA boy with left CDH and malrotation s/p left-sided CDH repair and Ladd's (3/6). Post-op course c/b abdominal compartment syndrome and AKI/RF requiring ex-lap (3/8) found to have intestinal/colonic perforations s/p resection, ileostomy, and silo placement. Now s/p silo take down and Alloderm placement (3/11) and stoma revision (3/13). Also with evolving BPD + lung hypoplasia now extubated on CPAP after DART course. History of feeding intolerance, now NJ fed.

**Events in Last 24 hours**  
-NJ replaced by IR and feeds restarted  
-Remains tachycardic following caffeine bolus, holding caffeine  
-Ostomy output decreased  
  
**Weight**  
**Last weight:**1.36kg (04/29/20)  
**Weight change:**-30g (04/28/20 to 04/29/20)  
  
**Plan**  
CV: HDS. Serial echos with VSD, PDA s/p Tylenol with most recent echo (4/25) w/ good function, no elevated RVP, and trivial muscular VSD.  **Noted to be tachycardic thought to be secondary to caffeine, holding dose for now.  Monitor.**  
Access:  PIV  
  
Resp: RDS, left CDH requiring mechanical intervention with SIMV and HFJV, extubated with DART to NIPPV (3/25), has since weaned to ram CPAP 7 21%. **Plan to leave on CPAP 7 through the weekend and consider wean to CPAP 6 on 5/1.** Increased spells requiring intervention, s/p caffeine bolus 4/27 with some improvement. Resumed maintenance caffeine 4/28 with plan for ~ 1 week course (currently on hold due to tachycardia).  HCTZ enteral.  Follow CXR and PRN gases.   
  
FEN: NJ dislodged and replaced 4/28.  Currently on Elecare 28 kcal via NJ @140/kg. On NaCl supps and famotidine. On iron and Vit D. H/o emesis with gastric feeds.Continue to monitor lytes, I/Os, growth. Lytes q Monday and PRN.  
  
GI: L sided CDH with liver involvement s/p open CDH repair in NICU (3/6), also with abdominal facial bridge with Gore-Tex to accommodate repair. Incidental malrotation, s/p Ladd's; still has appendix. Post-op period c/b compartment syndrome s/p ex-lap (3/8) with ileal/colonic perforations s/p resection, ileostomy, mucous fistula, silo placement. S/p repeat ex-lap (3/13) for silo takedown, removal of facial Gore-Tex and replacement w/ AlloDerm, partial skin closure, stoma revision (had sealed shut), now with bag. Monitor closely.   
  
Bili: Neonatal jaundice, s/p phototherapy. Dbili most recently downtrending to 0.3, continue to trend.  
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Heme: Anemia s/p pRBC transfusions (most recently 4/15). Will trend CBC weekly (next 5/1). **Rechecked CBC 4/29 in setting of tachycardia, Hct. 31%, Ret. 5.4% and RetHe 30.5, WBC 14.6  Continue Fe supplementation**.  
  
ID: No current infection concerns. s/p 5 day course cefazolin for cellulitis. S/p empiric ampicillin/cef/flagyl x 14 days after intestinal perforation.  Monitor.  
  
Renal: h/o AKI i/s/o abdominal compartment syndrome (anuria followed by polyuria).  Will avoid nephrotoxic meds, renally dose all medications and trend electrolytes.  
  
Immunology: NBS initially with low TRECs, but highly likely to be secondary to prematurity and illness, correlates with the low lymphocyte count. Immunology added on lymphocyte subsets (3/7), will repeat in few weeks. Memory panel pending. T cell mitogen proliferation recommended but 5ml, d/w Immunology and most recent NBS with normal TRECs.  
  
Neuro: HUS (2/17) sluggish flow through anterior sagittal sinus, small L>R subdural fluid collections. HUS 2/20, 2/22, 3/2, 3/7, 3/9, 3/22 without IVH. **Obtain term HUS** **week of 5/1.**  
  
Sedation: No current sedation.  
  
ROP (4/12): zone 2 immature, 4/19: R stage 1, zone 2, L stage 1, zone 1-2. **Follow-up 1 week,** **exam week of 4/26 deferred due to spells, next week of 5/1.**  
  
Genetics: Dysmorphic features including low set posteriorly rotated ears, camptodactyly, VSD, CDH. Genetics consulted, rapid CMA with VUS, karyotype sent 3/14. WES sent, findings of multi gene duplication.  
  
Social:  Family from MA, with 6y, 4y, 1y and triplets. Mom visits regularly. Will continue to inform and support family. Most recent family meeting 3/22 with NICU team and Dr. Earhart to discuss overall course and steroids.  
  
RHCM:  
- Newborn screening: 2/19: low TRECS, 3/2:normal TRECS, 3/19 with AT, abnormal TRECs, leucine, and hydroxyproline. Repeat sent 3/28, normal TRECs, AFT. **Send per protocol, next 5/1.**

- Hepatitis B Vaccination: did not receive  
- Other Vaccinations: 2 mo vaccines given 4/19. No live vaccines per Immunology until can demonstrate adequate Ab response to inactivated vaccines at ~ 6mo age. .  
- CCHD: N/A, had ECHO  
- Hearing screen: Will need prior to discharge  
- Car seat testing: Will require prior to discharge  
- Circumcision: Will inquire as to parents preference  
  
PCP: Will ask parents and update.  
  
Disposition: NICU as recovers from CDH repair and issues related to premature birth.