**NOTE 4**

**PATIENT 1002**

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| **DATE: 3/21/20**  **Patient Summary** Patient, triplet A, is a 3+ week old 27 4/7 wks GA male infant with prenatal diagnosis of left CDH. RDS initially on HFJV, NPO, vygon to suction. S/p open left-sided CDH repair with Goretex patch, fascial bridge with Goretex patch, skin closed, malrotation s/p Ladd's (still with appendix) on 3/6. Post-op worsening hypotension, AKI/RF, s/p ex-lap 3/8 found to have intestinal/colonic perforations s/p resection, ileostomy, fistula, silo. Additional CVL dl placed 3/8. Now s/p polyuria, resolved AKI, transitioned to SIMV on 3/11 for silo takedown, with removal of facial Goretex and placement of alloderm, stoma revision 3/13, back on HFJV.   **Events in Last 24 hours** - morphine increased to 0.13 - continues to be tachycardic - sodium still low despite going up in PN - sepsis work up thus far negative - had dilation of his ostomy this morning with surgery  **Weight** Last weight: 1.1kg (03/21/20) Weight change: +50g (03/19/20 to 03/21/20)  Intake and Output **Today's:  ( 07:00 - 09:43 )** Intake Totals:  1.04 mL Output Totals: 0.0 mL Balance:  1.04 mL  **Yesterday's:  ( 07:00 - 06:59 )** Intake Totals:  134.51 mL Output Totals: 63.0 mL Balance:  71.51 mL  **Extended Vital Signs**   |  |  |  |  | | --- | --- | --- | --- | | **Vitals Signs since (03/20 09:43)** | **24 h min** | **24 h max** | **Most recent (Time)** | | Temperature Axillary | 35.2 | 37.1 | 35.2           (09:00) | | Heart Rate | 163 | 198 | 168          (09:00) | | Respiratory Rate | 0 | 78 | 21             (09:00) | | Systolic Blood Pressure | 55 | 69 | 67           \*08:00\* | | Diastolic Blood Pressure | 26 | 32 | 32           \*08:00\* | | Mean Arterial Pressure (Device) | 36 | 47 | 47           \*08:00\* | | Blood Pressure Location |  |  | Right upper       \*08:00\* | | Oxygen Saturation (SPO2) | 76% | 100% | 76%       (09:00) | | Oxygen (L/min) Delivery Device |  |  | Other: HFJV       \*01:25\* | | FiO2 | 0.3 | 0.5 | 0.4       (09:00) | | Oxygen (FiO2) Delivery Device |  |  | Ventilator       (09:00) | | Transcutaneous CO2 (PtcCO2) | 41 | 109 | 72           (09:00) | | Observations/Comments |  |  | Surgery at bedside to dilate ostomy       \*07:00\* |   ----------------------------------------------------------------------------------   **Plan** Baby boy, triplet A, is a 2+ week old 27 4/7 wks GA infant with prenatal diagnosis of left CDH. S/p bedside open left CDH repair with Ladd procedure (without appendectomy) 3/6. Anuria post-op despite fluid resuscitation, now s/p bedside reopening on 3/8 with findings of perforation and s/p ileocecectomy, end ileostomy, and silo placement. Subsequent polyuria now normalizing and s/p OR 3/13 with reopening of recent laparotomy, removal of silo and Gore-tex mesh, Alloderm mesh closure of fascia, and partial skin closure. Currently NPO, on HFJV.  *CV:* S/p SDS X24h on admission. Echo 2/18 with large PDA with bidirectional flow, PFO with left to right flow, small anterior mVSD with bidirectional flow, normal function. Repeat echo 2/24 showed large PDA with bidirectional flow and some suggestion of adding to pulm edema, has PFO. PHTN team following. Repeat ECHO 2/27, 3/3, and 3/8 with closed PDA. **-** s/p acetaminophen (2/24-2/28, initial plan for 7 day course) - Restarted SDS 3/7 --> discontinued 3/10 --> restarted 3/13 --> discontinued 3/14 - S/p pressors (dopa, epi, norepi) **- Goal MAPs 35-45 - persistently tachycardic, though to be due to discomfort on the high frequency ventilator - plan for repeat ECHO for pulmonary hypertension today**  Access: s/p low lying UVC (2/17 -2/18), s/p UAC (2/17-3/10), SL PICC (2/18- 3/17), tunneled DL CVC (3/8 - ). - Stable non-occlusive thrombi on US 3/7  *Resp:*  Intubated in the delivery room with 2.5 ETT and started on high frequency ventilation (HFJV), s/p surf x1. Transitioned to conventional ventilation 2/18 but went back on HFJV for worsening gases. Transitioned to conventional ventilation 3/11 but went back on HFJV 3/13. Transitioned from HFJV to CMV 3/16 but derecruited and so was placed back on HFJV. - wean ventilator as tolerated - daily CXR - gases daily and with vent changes - on daily caffeine (currently held for tachycardia)  *FEN:* H/o hyperglycemia improved off stress dose hydrocortisone. - NPO **- TF 120 mL/kg/day given concern for pulmonary edema - s/p 1x diuril 3/18 and 3/19** - PN/Omegaven - monitor urine output and electrolytes closely **- continues to have low sodium, will increase in PN** ----------------------------------------------------------------------------------- *GI/Bili:* L sided CDH with liver up. S/p bedside open L CDH repair 3/6 via left subcostal incision, found to be large CDH (type C defect) containing left lobe of liver, stomach, spleen, small bowel and colon. S/p bedside reopening on 3/8 with findings of perforation and s/p ileocecectomy, end ileostomy, and silo placement. S/p OR 3/13 with reopening of recent laparotomy, removal of silo and Gore-tex mesh, Alloderm mesh closure of fascia, and partial skin closure. **Stoma dilated and opened at bedside 3/20 by surgery.** - Vygon CLWS - awaiting stoma output to remove vygon and consider feeds  *Renal:* - h/o AKI, anuria post-op 3/6 until 3/8 PM, Cr normalizing - Polyuria now resolving - renal US 3/7 with "echogenic renal cortices with abnormal main renal arterial waveforms and elevated resistive indices; constellation of findings likely reflect medical renal disease/acute kidney injury"  *Heme:*S/p multiple pRBCs - Continue to follow Hct - most recently wnl 3/18 AM - Ongoing thrombocytopenia of unclear origin, improving - s/p 15 ml/kg pRBC 3/17 given low hct  *ID:*No risk factors for sepsis (delivered by C-section with intact membranes for twin reasons). Twin C (singleton, did not share a placenta or sac) developed coryneform bacteremia - being treated with amp/gent/vanc. Blood culture final NGTD - Urine CMV negative 3/3 **- 3/7 obtained blood culture, resp culture, unable to obtain urine culture, and started cefepime and zosyn --> switched to cefepime, ampicillin and flagyl, plan for at least 2 week course from OR - following blood, urine, and trach cultures**  *Neuro:*HUS 2/18 with bilateral subdural hemorrhage, difficult to visualize anterior superior sagittal sinus. Repeat 2/20 with subdurals decreased in size. HUS stable 2/23. s/p tylenol x72 hours post-op. **-** fentanyl --> transitioned to **morphine gtt 2/28** **-** maintain goal SBS -1 **-** HUS 3/9 stable, **due for repeat this week**  *Immuno*: NBS x2 with low TRECs. - Immunology added on lymphocyte subsets 3/7, will **repeat in 2-3 weeks (or when ALC normalizes)** as well as T cell memory panel **- Will send T cell mitogen proliferation when able to send volume (5cc)** - Please **hold all live vaccines** (rotavirus, MMR, VZV) until patient can demonstrate adequate specific antibody response to inactivated vaccines (to be checked around ~6 months of age) ----------------------------------------------------------------------------------------- *Genetics* - consulted, **rapid MCA and karyotype sent 3/14 - Microarray with finding of unknown significant, copy gain of 14q11.2 - plan for whole exome**  *Social:* Continue to update and support family. Last family meeting 3/3. Plan for family meeting 3/22.  *Disposition:* 11 Hale, critically ill premature neonate.  *RHCM:* - Newborn screening:    - 2/17: multiple unsatisfactory, **OOR SCID**    - 2/19 (DOL2): OOR aminoacidopathies (methionine), OOR T4 (low), **OOR SCID**    **-**3/2 (prior to transfusion): OOR aminoacidopathies (methionine and valine), AFT    - **3/19 (DOL30) pending** - Hepatitis B Vaccination: Deferred given < 2 kg - Other Vaccinations: - CCHD: n/a, got echo - Hearing screen: Prior to discharge - Car seat testing: Will require prior to discharge - Circumcision: Will inquire  PCP: Will ask parents closer to potential discharge  Halley Camp, MD/PhD Neonatology Fellow  Bailey Teare, MD Pediatric Surgery Attending | **Relevant Labs**   | **Test Name** | **Test Result** | **Date/Time** | | --- | --- | --- | | pH Venous | 7.264 pH (Low) | 03/21/2020 08:40 EDT | | pCO2 Venous | 74.7 mmHg (High) | 03/21/2020 08:40 EDT | | pO2 Venous | 30.2 mmHg | 03/21/2020 08:40 EDT | | Bicarb Venous | 34 mmol/L (High) | 03/21/2020 08:40 EDT | | O2 Sat Venous | 52.3 % (Low) | 03/21/2020 08:40 EDT | | Oxygen dissociation p50, Venous | 29.1 mmHg | 03/21/2020 08:40 EDT | | Sodium, Whole Blood | 128.0 mmol/L (Low) | 03/21/2020 08:40 EDT | | Potassium, Whole Blood | 4.1 mmol/L | 03/21/2020 08:40 EDT | | Chloride, Whole Blood | 94.0 mmol/L (Low) | 03/21/2020 08:40 EDT | | Anion Gap, Whole Blood | -0.4 mmol/L (Low) | 03/21/2020 08:40 EDT | | Glucose, Whole Blood | 91.0 mg/dL | 03/21/2020 08:40 EDT | | Calcium Ionized | 1.35 mmol/L (High) | 03/21/2020 08:40 EDT |   **Relevant Diagnostics Images/Studies**  PROCEDURE: XR-Chest 1 View   REPORT FLAG: None   IMPRESSION:    1.Unchanged appearance of the chest with interstitial edema superimposed on chronic coarsened interstitial markings likely underlying chronic lung disease of prematurity and atelectasis. No new focal consolidation.    2.Unchanged small left-sided pleural effusion   [1] |