

**Facilitated Mini Training – Story**  
**“Primary Care for Children with Complex Congenital Heart Defects”**

**Instructions:** The story below presents the example of how to provide primary care for children with complex congenital heart defects (CCHD). Throughout the story, different types of important wellness considerations in care for children with CCHDs (as outlined in the accompanying training slides) are identified. It is recommended that the story be presented and discussed during the training. Refer to the discussion questions/possible answers below to guide the conversation in your practice.

*Types of important wellness considerations in care for children with CCHD:*

1. Nutrition
2. Immunizations
3. Respiratory syncytial virus (RSV) prophylaxis
4. Subacute Bacterial Endocarditis (SBE) prophylaxis
5. Exercise

**Case Study, Part 1:**

Isabelle is a 4-month-old infant with hypoplastic left heart syndrome, diagnosed prenatally. She has undergone 2 cardiac surgeries. Her first surgery was the Norwood and Blalock Thomas Taussig shunt at 4 days of life and required hospitalization for 2 weeks. She was initially discharged on nasogastric feeds and was having difficulty gaining weight. She was being fed with expressed breast milk but due to the poor weight gain, caloric concentration of the breast milk was increased to 24Kcal/oz formula. She was also started in speech therapy to allow her to improve oral motor skills. She did well overall and underwent a cardiac catheterization at 3 months of age and Glenn surgery at 3.5 months of age. She was in the hospital for 1 week at that time and was discharged home on oral feeds. She presented in the primary care clinic 2 days after being discharged from the hospital and is currently taking furosemide BID (twice daily). She is due for her 4-month immunization, and it is currently September. Her baseline saturations are 82% on room air.

**Question:**

What are some data points you will need to complete this initial visit?

**Suggested Answers:**

- Length and weights since birth, along with recent hospital discharge weight in order to ensure she’s gaining weight and growing well now on oral feedings.

- Vaccination history and history of being on cardiac bypass & use of any transfused blood products. Since it's only been 2 weeks since her most recent heart surgery, her cardiothoracic surgeon may want you to wait 4 -6 weeks from date of surgery before resuming her normal schedule of infant immunizations. If she received only packed red blood cells during her surgery, there likely won't be any live vaccines (MMR, Varicella) due before the recommended 6-month period after transfusion passes. However, the table below is a good reference for "how long after which blood product" one should wait to resume live vaccines to ensure they are efficacious.
- Find out if the family has adequate supply of and understand how to measure her Furosemide.
- Establish a plan for palivizumab prophylaxis ordering. As the cyanotic CCHD is incompletely repaired, this patient's cardiologist would recommend palivizumab, and as it is September, dosing will need to start in the coming 1-2 months. The primary care provider (PCP) should ensure the patient has had palivizumab ordered and that there is a plan for location of monthly injections.
- Day/time of cardiology follow up and post-operative follow up with the surgeon (which may be coordinated together at the surgical center). Would recommend following this patient at least monthly for weight checkups in the primary care clinic.

### **Case Study, Part 2:**

Isabelle is now an adorable 5-year-old with palliated hypoplastic left heart syndrome with non-fenestrated Fontan. Her baseline saturations remain in the mid 90s in room air. She is planning to start in kindergarten this fall, but her mom has concerns that she'll catch lots of viral illnesses that will harm her health. Her weight and height are steadily climbing along the 25th%ile and 15th%ile curves for age on a typical oral diet. She knows most of her colors and can sing the "ABCs", but mom's concerned that her other children could "count to 10" by now, and Isabelle is struggling with that.

### **Question:**

What can be done to protect this patient from acute viral illness as she enters school?

### **Suggested Answers:**

- Isabelle should receive the annual Influenza vaccine and should stay up to date on COVID-19 vaccines (or according to updated guidelines). Patient is now too old to receive palivizumab prophylaxis for RSV (only available for up to 2 winter seasons during/after infancy).

- Mom should encourage hand hygiene, avoidance of heavily crowded environments in winter season when able and consider masks when crowds can't be avoided. Otherwise, Isabelle should attend school as that is the best way to ensure proper educational access and identification of any exceptional developmental needs.

## Reference:

[Timing and Spacing of Immunobiologics](https://www.cdc.gov/vaccines/hcp/acip-recs/general-recs/timing.html). TABLE 3-6. Recommended intervals between administration of antibody-containing products and measles- or varicella-containing vaccine, by product and indication for vaccination. <https://www.cdc.gov/vaccines/hcp/acip-recs/general-recs/timing.html>

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