



**Questions from Feeding the Infant with Congenital Heart Disease Webinar,  
presented by Kelly McKenna, February 14, 2019**

1) How do you "work around" tongue tie?

I probably used incorrect wordage with "work around". I will educate parents that the risks of a frenulectomy are high for the single ventricle population, so will not be addressed during the initial acute admission.

2) What are things to look for that may indicate vocal fold paralysis?

#1. Vocal quality. All babies tend to be a little hoarse following extubation. Babies with vocal cord dysfunction will have minimal voicing. And you will notice that it doesn't improve over several days. With feeding, you will likely see outright coughing, upper airway congestion, wet vocal quality, gagging, or lack in interest in feeding (babies can be smart about self-preservation!)

3) Do you have a cardiac follow up clinic, where you can follow these children after discharge?

Yes. After discharge, many of the children are seen in our multi-disciplinary cardiac neurodevelopmental clinic. They receive therapies in our heart center, so that we have access to the team as needed. It has been quite successful for us so far.

4) Do you do your MBS studies in sidelying for VCP babies and/or if they aspirate in semi-upright do you have a hard time getting staff to PO ONLY in sidelying?

When the radiologist is agreeable, we will do sidelying. And yes, it can be challenging to get everyone on board with sidelying! We try to post signs as gentle reminders.

5) You mentioned using the Dr. Brown's specialty feeder with infants who fatigue: are you concerned with the infant not fully developing appropriate sucking skills given the compression only mechanism of this bottle with valve?

It's not always the first thing we try. But, if we feel a family may not comply with tube feeds at home, it has been a "better" option. The goal is to get them back to a standard system ASAP.

- 6) I can appreciate your breast-feeding protocols, and approach to creating a uniform gavage supplemental program. I have tried a similar time frame policy, but our program has supported it without any evidenced based information. How do you support your protocol in your unit - or is it just generally accepted based on success in your hospital?

The protocol was developed by the lactation team and initially rolled out in our NICU. It's still a work in progress on our unit, as the CVICU team likes to know actual numbers. Often, we rely most on how the baby is growing/gaining weight.

- 7) What causes the emesis?

In general, emesis or any feeding intolerance is related to poor gut perfusion. If the digestive system is not getting enough blood circulating to digest food, it will result in some level of intolerance.

- 8) Would it be possible to get a larger copy of the developmental pyramid?

Yes, exploring the ability to provide this.

- 9) Do you routinely do MBS studies on the complex CHD children, who are at risk for aspiration or wait until they present with symptoms of aspiration?

The babies with known vocal cord dysfunction all get MBS or FEES once they are ready. We need them willing to take at least SOME po in order to get valid studies. With the others, it's often based on clinical judgement. I'm lucky in that I have a team who listens and trusts my judgement.

- 10) Have you seen that babies with ASD have issues with feeding because of the ASD?

Many times, we hear cardiology say it doesn't impact PO, but I'm not convinced. In my experience, yes. But I've also seen some feed reasonably well.

- 11) Does your program use FEES with these infants?

YES, but it's still NEW. So far, we've used it only on a small number of children. ENT has been the one scoping on the patients we've done it on so far.

12) Do you know if there are any plans for Dr. Brown's bottles to develop a wider based nipple for our lower tone babies with Trisomy that also need the slow flow with their oral motor hypotonia in addition to their cardiac status?

Yes, per Dr. Brown's, they just released a wide-neck bottle with a new design and can be requested for a sample by emailing [medinfo@drbrownsmedical.com](mailto:medinfo@drbrownsmedical.com)