Oley Virtual Mini Meeting
Ask Me Anything Q&A

Thanks to Coram/CVS specialty infusion services for sponsoring this session and providing the following responses to participants’ questions.

Q: In long term HPN users, is iron deficiency a problem? How is this monitored?

A: Iron deficiency can and does occur with long term HPN use. Your physician can order regular lab monitoring of your hemoglobin, hematocrit, serum iron, transferrin saturation, and ferritin to assess for iron deficiency and anemia that may result from inadequate iron stores. It is recommended to check these labs every three months.

Q: Would like to hear the facts about shortages of TPN raw materials or supplies that I see people discussing online; thanks

A: As of October 18, 2021, there are shortages of several TPN components: sodium phosphate, potassium phosphate, sodium acetate, and potassium phosphate. Pfizer, the manufacturer of these products released a letter to customers informing of the shortage and the cause, which can be found on the American Society of Parenteral and Enteral Nutrition (ASPEN) website: https://www.nutritioncare.org/uploadedFiles/Documents/Guidelines_and_Clinical_Resources/Shortages/Availability_Update_Sodium_Phosphates_Potassium_Phosphates_Sodium_Acetate_Potassium_Acetate_-_Customer_Letter_8-24-21.pdf

Q: How do you educate patients about need for product changes or shortages with their parenteral nutrition?

A: Coram clinicians collaborate with prescribers to recommend changes to the TPN prescription in times of shortage. The change is then communicated to the consumer or caregiver, by the dietitian or pharmacist. If you have questions, start with your homecare clinician – they likely have the answer.

Q: Solutions for managing day-to-day setup when the patient has pain and/or limited mobility of the hands and/or arms
A: With TPN, stability can be a limiting factor, but in some cases where a care giver is not present to help with additives, the pharmacy may be able to send 2 shipments per week with the additives compounded in the mix room, or already drawn up into syringes by your pharmacy. Safety is a priority so if you feel that limited dexterity is compromising a safe hook up, work with your physician and home TPN clinicians to come up with an individualized plan.

Discuss your challenges and ensure that pain is being properly addressed by your care team when it is impacting your daily functioning. If you have a time of day when pain is better managed allowing a higher level of functioning, then schedule your daily set up routine around that. Consider enlisting the help of a friend or family member who is able and willing to learn to assist. Check with your homecare clinician to verify your particular situation but most home TPN regimens are cyclic for 8-12 hours and the formula is stable for 24 hours at room temperature once mixed. This allows patients some flexibility with enlisting help with daily setup even if the person is not able to be present at the time of day that the patient starts the daily infusion.

Q: Is it appropriate to check gastric residuals with a G-tube? If yes, what are the guidelines as to what is normal or abnormal?

A: Checking residuals is not a standard of practice for assessing tolerance or reducing risk of aspiration. Instead, tolerance is measured by other signs and symptoms such as ongoing nausea, vomiting, diarrhea, constipation, gas, and bloating. To reduce risk of aspiration, the standard of care is to ensure head of the bed elevation of 30 degrees or more for 30 minutes before feeding, during feeding, and 30 minutes after feeding. Your homecare dietitian or physician can help you determine how to manage symptoms of intolerance or make changes to the tube feeding if warranted.

Q: I have Protein Losing Enteropathy causing malnutrition and blood volume loss, what are the statistics for remission/cure?

A: This really depends on the cause of the protein losing enteropathy. For example, if this was caused by problems with the liver and pressure in the veins in the liver, there are some treatments which can improve a patient’s symptoms. Conversely, if the cause is unknown or is from a disease of the small intestine of which there is no treatment, the chances of remission or cure are less common.

Q: Proper care of the stoma site. Cause of extreme odor of flatulence and stool?

A: Odor in the stool is from the bacteria in the stool and their production of hydrogen sulfide and other gases. There have been many proposed treatments to reduce unpleasant smells. This can include limiting sulfur containing foods in your diet, reducing sulfur containing medications and the use of over-the-counter supplements such as chlorophyllin, odafree and probiotics.
Q: How do I transition from overnight Gtube feeds and Pedialyte, to eating food and oral Pedialyte? All my son will eat is bread

A: Some children have oral feeding intolerance or aversion related to long-term feeding tube use. Your physician and dietitian can recommend strategies to gradually increase the volume and variety of foods. For additional recommendations, Feeding Matters is a non-profit advocacy group that can help you find resources to help with a pediatric feeding disorder: https://www.feedingmatters.org/

Q: Which formulations of TPN lipids have been best for any patients you may have with Mast Cell Activation Syndrome.

A: There is no guarantee of any lipid having improved tolerance with Mast cell activation syndrome. It requires the test use of a lipid for tolerance in a setting where personal are prepared to handle acute emergencies such as difficulty breathing, very low blood pressure and passing out.

Q: Any word on if the Bodyguard Pump will be coming back?

A: The most recent update on the Bodyguard pump can be found here: https://www.fda.gov/medical-devices/medical-device-recalls/cme-america-updates-recall-bodyguard-infusion-pump-system-due-risk-over-and-under-infusion

Q: How can I get my Ins. To use Coram instead of the lousy DME for liquid hope

A: If the homecare provider of choice is not in your insurances’ network, you may check with your insurance to see if out of network benefits are part of your plan. Keep in mind using out of network benefits may incur a higher co-pay or co-insurance.

Q: If you don’t have access to a wound care nurse, what kind of doctor/specialist should you see for stoma skin concerns?

A: The best doctors are general surgeons or GI surgeons.

Q: I’m interested in new science and upcoming treatments for Short Bowel. Can you point us toward research in this area?

A: The National Organization for Rare Diseases keeps a database of investigational therapies for SBS and resources for those with the disease at https://rarediseases.org/rare-diseases/short-bowel-syndrome/#investigational-therapies

*Note from the Oley Foundation: Other resources include the following pages on the Oley Foundation’s website: “Join a Study” (oley.org/Join_A_Study) and oley.org/ShortBowelSyndrome.
Q: Can anyone tell me where to purchase a large luer tip syringe for bolus enteral feeding? as big as 500 ml?

A: At Coram, we offer our patients who desire larger bolus feeding methods a 140ml catheter tip syringe made by Cardinal. We also offer the Bolee Bag feeding system with an ENFit connection which allows for a 375ml feeding. There are online retailers that offer non-medical grade supplies, where larger 500ml syringes are available including Luer tip.

Q: Are there any medications or specific diets to support a child with short bowel with chronic diarrhea to get adequate nutrition

A: Speaking generally, yes – a diet for short bowel syndrome is suggested but may need to be modified and adjusted based on the severity and longevity of the diarrhea. It’s best to work with a registered dietitian to slowly make changes and monitor the response. Diet recommendations are divided into two categories: diet for those with an intact colon, and diet for those without an intact colon. Laura Matarese wrote a great article for Oley with some of the basics, which can be found here: https://oley.org/page/DietaryMgmt_SBS/Nutrition-andYou-Dietary-Management-for-Short-Bowel-Syndrome.htm

Q: I’ve made a slow process of gaining a bit of weight will there be a time of increasing the caloric intake. Dr. says not now. Thx

A: It may be helpful to talk to your dietitian about your nutrition goals. They can make a recommendation and collaborate with the physician to increase calories to promote weight gain, while monitoring to ensure tolerance.

Q: Do you have a local office in Florida

A: Yes, Coram has pharmacies in Jacksonville, Miramar/Miami, Tampa, and Pensacola.

Q: What type of line do you recommend to someone who has had multiple migrate despite proper securement (likely because of EDS)?

A: If you are having problems with catheter migration from Ehlers Danlos Syndrome (EDS), the catheter location should be placed in a location that has the least skin flexibility to prevent the catheter from being pulled in and out of the entry site. In some patients, a tunneled catheter or a PORT may make more sense. However, because of the poor wound healing in some people with EDS this should be discussed with your physician and care team.

Q: How do you best to deal with pain and running a feeding tube and how to incorporate it into your daily schedule and up the rate.
A: First and foremost, address any complaints of pain with your physician. Consider a pump backpack if you haven’t already which allows you to go out and about your day while infusing your tube feeding. Work with your homecare dietitian and physician to adjust your formula, pump rate and duration to decrease the hours necessary on the pump. There are many options to your homecare regimen that can be considered with the help of your homecare dietitian and physician.

Q: Do Gtube and J tube sites get too old and need to be closed and new sites be made? I have had these sites for over 15 years.
A: There is no time limit on how long a site can be used. In general, sites for feeding tubes are not changed unless there are complications that cannot be resolved with treatment.

Q: Is there a way to optimize medications given through GJ tube for better absorption, i.e. seizure medications?
A: One common seizure medication is most effective when taken fasted, meaning that you have not had any enteral nutrition intake in the previous 2 hours. The medication can easily fit between feedings when using a bolus regimen. For example, bolus at 8 am, medication at 10 am, next bolus at 12 pm. If you are on nocturnal pump feeds, consider taking your medication 2 hours after stopping your feeding in the morning. If you are on twenty-four hour feeds, you may need to make a change to your regimen to allow a four hour break to take your medicine (2 hours before and after). Your dietitian can help adjust your feeding to a twenty hour regimen.

Q: What advice do you give your clients who want to stay with your pharmacy when it is out of network with new insurance?
A: Some insurance plans have out of network benefits; however, this typically results in a significantly higher co-insurance or co-pay, and a higher deductible. Self-pay is also an option, although most people would rather not self-pay when they have coverage through insurance. Lastly, you could research changing your insurance plan if feasible.

Q: How do I know I have the right size tube and how much leakage from a mickey tube is normal?
A: Leakage from a tube site should be addressed. The amount of leakage can vary greatly depending on a wide variety of reasons. Many patients will not experience any leakage. To reduce the risk of leakage, ensure the following:

1) For a balloon style tube or button, verify that the balloon is properly inflated to the recommend fill volume. Once fill volume is verified, reassess the fit.
2) A properly fitting button or dangler style tube will not have significant movement in and out of the stoma. The button or external bolster should rest just above the level of the skin (no more than the width of a dime) without exposing the stem of the button or tube.

If the leakage you experience is occurring right after a feeding, this could be a sign that you are feeding too fast, or too much volume at one time. Slowing down the feeds or feeding smaller volumes at the feed may help to reduce this type of leakage.

Q: Do any of the HEN products contain prebiotics, probiotics, antioxidants and other nutrients that are available in plant foods?
A: Yes, many HEN products provide some nutrients that are considered to be antioxidants. There are a number of formulas with prebiotics added. Plant based formulas are also now widely available.

Q: Why can’t I find a better way to hold my tube still other than taping I’m getting tape burns
A: You might consider trying a securement device. Your homecare dietitian can make a recommendation.
*Note from the Oley Foundation: Additional suggestions may be found at oley.org/Protecting_Securing_LinesTubes.

Q: How can I find a tube feeding supplier/vendor?
A: Ask your insurance company which home enteral nutrition providers are in network with your plan. Then, it’s a good idea to seek out the opinion of a clinician on the homecare company they like to work with.

Q: How can HPN patient be prepared for disaster when shelf life of PN is only 7 days?
A: Hopefully you received some good tips from Catherine Goodhue during the Emergency Preparedness presentation. You can talk to your home infusion provider about obtaining several days’ worth of shelf stable TPN product to keep on hand. There are both lipid-free and lipid-containing formulations available. Your pharmacist, dietitian, and physician can guide you to the best product for you.
*Note from the Oley Foundation: Catherine Goodhue’s presentation can be viewed at oley.org/2021minimeetingpresentations. Additional resources can be found at oley.org/emergencyprepared.