Oley Foundation Mini Meeting | October 15, 2021

11:00 AM – Introductions

11:10 AM – TPN Perspectives Through the Ages – Jerry and Dotty Fickle, Willie Griffin, Nicole Pelletier and Kayla Pfab; moderated by Michael Medwar

11:35 AM – Preserving Vascular Access – Mark DeLegge, MD, FACG, CNSP, AGAF, FASGE, Nutrition Support Medical Director; Coram CVS/Specialty Infusion Services

12:10 PM – Emergency Preparedness for Individuals Requiring TPN – Catherine Goodhue, MN, RN, CPNP; Children’s Hospital Los Angeles

12:45 PM – BREAK

12:55 PM – Sponsor coordinated session presented by Coram CVS/Specialty Infusion Services

Ask Me Anything! During this interactive session, our Coram TPN and tube feeding team will answer your burning questions. From tube site and catheter care, to adjusting your nutrition regimen to meet your lifestyle goals, to weaning off nutrition support therapy altogether, we’ve got the expertise you’re looking for! Joining us will be Leah Bufka, RD, LD, CNSC, Lead Dietitian, TPN; Janelle Flaherty, RD, CNSC, Enteral Operations Dietitian Manager; Crystal Wilkinson, PharmD, RPh, TPN Pharmacist; Sarah Simonetti, BS, RN, Corporate Clinical Nurse; Mark DeLegge, MD, FACG, CNSP, AGAF, FASGE, Nutrition Support Medical Director; and Michael Medwar, Patient Advocate.

1:25 PM – Gastroparesis and Pain – Kenneth Koch, MD, Professor of Internal Medicine, Section of Gastroenterology, Wake Forest University Baptist Medical Center

2:00 PM - Closing Remarks
Our Speakers

Leah Bufka, RD, LD, CNSC
Lead Nutrition Support Dietitian, Infusion
Coram CVS/ Specialty Infusion Services

Leah has been a dietitian for 11 years and with Coram for almost 5. She currently lives in Colorado Springs, CO but as Lead RD she gets to help out around the whole country.
Nutrition Super Power: Ability to teach peers and work the same question from different angles to better their understanding of new subjects

Mark DeLegge, MD, FACG, CNSP, AGAF, FASGE
Nutrition Support Medical Director
Coram CVS/ Specialty Infusion Services

Mark DeLegge completed his medical degree at the University of Maryland followed by a residency in Internal Medicine at the University of Connecticut Health Center and a fellowship in Gastroenterology/Hepatology and Nutrition at the Medical College of Virginia. He is board certified in Internal Medicine, Gastroenterology and Nutrition. He was a faculty member and a full Professor of Medicine within the Division of Gastroenterology at the Medical University of South Carolina where he served as Director of the Digestive Disease Center. He is extensively published and has been a frequent invited speaker nationally and internationally. He served as the Global Senior Medical Director for Baxter Healthcare form 2010-2016 where he led efforts in drug development, clinical trial design, registration package development and submission, business strategy and innovation. He serves as medical director for Coram Healthcare. He is a partner in DeLegge Medical which provides medical educational programs, nutrient, drug and medical device regulatory and clinical package assessments and acceleration and medical market assessment and strategy.
Janelle Flaherty, RD, CNSC  
Enteral Dietitian Manager  
Coram CVS/Specialty Infusion Services

Janelle is the manager of Coram’s Enteral Operations Dietitian and Medicare Qualification teams. She has been a dietitian for 14 years, working with tube feeding patients with Coram for 12 years. She lives in Cascade, Idaho, about 2 hours north of Boise.  
**Nutrition Super Power:** Knowledge of enteral parts and pieces, and troubleshooting feeding tube connection issues.

Jerry and Dotty Fickle  
New Haven, Indiana

Jerry was born in 1942. In high school they discovered that he had Crohn's and after many surgeries, he ended up with short-bowel syndrome. In 1981, he started on TPN and has been on it for nightly feedings for 40 years. He lives a normal life, playing golf, traveling with his wife Dotty, and now enjoying retirement after teaching elementary physical education for 29 years. He started attending Oley conferences back in the 80's and they have provided a lot of good advice throughout the years.  
Dotty was born in 1942 in Springfield, OH and grew up there. She attended and graduated from Indiana University in 1964. Dotty started teaching in West Lebanon, IN where, after 3 years, she met Jerry when he was hired as a new teacher/coach. They married in 1968 and have been together for 53 years! Dotty taught until 1995 when she took an early retirement and enjoyed playing softball, and now tennis and pickleball. They have taken a lot of bus trips and also try to get to Florida for part of the winter when they can. After 3 years of not being there, thye are hoping to go this year again, if COVID cooperates!
Ms. Goodhue is a Pediatric Nurse Practitioner (PNP) with over 30 years of pediatric experience. Currently she is the Outpatient Trauma Clinic PNP at Children’s Hospital Los Angeles. She has been involved in pediatric disaster preparedness research since 2007. She has explored the preparedness levels of families with a child on TPN and ways to improve their preparedness levels.

Professor Willie Griffin Jr started his training in Martial Arts in 1964 in Newark, New Jersey, under Grandmaster Bill Wilson and Charles Wilson in the art of Goshi Shun Karate – Do. He is one of the top competitors in the martial arts arena. His awards and accomplishments include: three World Championship Title Belts, over fifty grand championship titles, in Kata, Weapons, and Fighting and Breaking. Professor Griffin was inducted into two Hall of Fames: The Action Martial Arts Magazine and Karate World Black belt Hall of Fame. He also received The Living Legends Award, and Supervisor of the Year Award from the Mayor and Police Commissioner of Irvington, New Jersey, for teaching Police officers and citizens self-defense. In 2013 he received the award as A Goodwill Ambassador to the Martial Arts. For over forty-eight years he has studied various martial Arts, he holds a Seventh Degree Black Belt in the Kermite Matial Art System, and a Fourth Degree Black Belt in Shotokan Karate – Do.

He also taught martial arts as a curriculum for the Board of Education in Howard County, Maryland and Randallstown, Maryland. Professor Griffin also studies acupuncture and holistic medicine, under Dr. Bruce Marshall, OMD, PhD. He is also a certified personal trainer. As a former employee of Black Entertainment Television, he’s been asked to do exercise and fitness segments on various occasions for the television show Teen Summit.
The study of martial arts is a way of life for Professor Griffin. His holistic approach is the foundation of his aura. His first rule is, that warriors do not consider martial arts training as a hobby or a game, but to a man of arms and weapons natural or manufactured. He is currently working on a class at Higher Dimension Christian Center, in Baltimore, Maryland and a book on self-defense awareness.

Kenneth Koch, MD
Professor of Internal Medicine, Section of Gastroenterology
Wake Forest University Baptist Medical Center
Winston-Salem, North Carolina

Kenneth L. Koch, MD, Professor of Medicine, Section on Gastroenterology & Hepatology, at Wake Forest Baptist Medical Center, has a career-long interest in understanding pathophysiological mechanisms of nausea and gastroparesis. Dr. Koch has studied extensively gastric myoelectrical activity (GMA) using serosal electrodes in animals and cutaneous electrodes in the study of normal 3 cpm GMA in humans. These studies have led to understanding gastric dysthyrias are present in various nausea syndromes. Importantly, a functional outflow gastroparesis subtype was described that reflects antro-pyloro-duodenal dysfunction. Response to endoscopic therapies with botulinum toxin A injection or balloon dilation or pyloroplasty in these patients is promising. The neuromuscular dysfunction of the pylorus is increasingly appreciated as a key factor in gastroparesis. Dr. Koch has successfully enrolled hundreds of patients with gastroparesis into studies for patients with idiopathic or diabetic gastroparesis and managed strong teams to support patient retention in these studies. For NIH-sponsored research studies, he has served as PI committed to active recruitment and excellent retention of patients. Dr. Koch is a PI in the NIH-sponsored Gastroparesis Clinical Research Consortium. Dr. Koch has written 160 peer-reviewed publications, 45 chapters, and 7 books.

Michael Medwar
Patient Advocate
Coram CVS/Specialty Infusion Services
Michael Medwar has been a patient advocate for Coram’s Nutrition Support Program since 2013 and an Oley Foundation member since the 1980s. He is a former member of the Oley Board of Trustees and the American Society of Parenteral and Enteral Nutrition’s Sustain national patient registry board. Nutrition Super Power: Empathy, having lived with Crohn’s disease since childhood and on TPN over a 17-year stretch, and having experience as a caregiver for his parents, who lived on nutrition therapy at different times, as well as his late brother, who was born developmentally disabled.

Nicole Pelletier  
Parent/Caregiver  
Fort Collins, CO

Nicole is the proud mother of a wonderful little preschooler who is kind, curious, smart, talkative, sassy, and also TPN-dependent. Shortly after their daughter’s birth, Nicole and her husband learned that their baby had Long-Segment Hirschsprung's Disease with "near total" aganglionosis, and following surgical intervention she also has Short Bowel Syndrome with only a short section of functional small intestine remaining. However, none of this holds their little one back from living her very best life!

Nicole's professional background is in developmental trauma and mental health, and she holds a Masters degree in Social Work from Boston College. Prior to her current role as a stay-at-home mom and her child's primary caregiver, Nicole had worked with children, adolescents, and adults providing trauma-informed individual and family therapy for 10 years. She and her family currently live in Colorado and enjoy hiking, making trips to the playground, taking bike rides, cooking, reading lots of books, and going on other fun adventures together!

Kayla Pfab  
President and Founder  
Transplant Unwrapped  
Dallas, Texas

Kayla is the president and founder of Transplant Unwrapped. Kayla’s medical journey began seventeen years ago when she hit her feet on a diving board and developed complex regional pain syndrome (CRPS). A few years later, she was diagnosed with an autonomic nervous system disorder, postural orthostatic tachycardia
syndrome (POTS), and chronic intestinal pseudo obstruction (CIPO). When Kayla began struggling to maintain her nutritional status via an oral diet, she researched her treatment options. It was at that point Kayla first discovered the Oley Foundation and the great resources it had to offer.

In 2015, Kayla was placed on intravenous (IV) hydration and parenteral nutrition (PN). In an effort to wean from PN, she received two intestinal transplants, including an isolated intestinal transplant in November 2015 and a modified multivisceral transplant (stomach, pancreas, duodenum, and small intestine) in February 2019. Even though Kayla remains on PN and IV hydration, she does not feel that this limits her in any way. She believes that staying positive is all about doing the things you love and living your life to the fullest every day.

Kayla earned a Bachelor of Health Sciences from Duquesne University and has a passion for helping and educating others. She currently lives in Dallas, Texas, with her family and in her free time enjoys riding her bike, baking, and traveling.

Sarah Simonetti, BS, RN
Corporate Clinical Infusion Nurse
Coram CVS/Specialty Infusion Services

Sarah has been a nurse for 28 years, and has worked in home infusion with Preferred Homecare and Coram for 20 of those. She is a leader on Coram’s corporate clinical team, supporting our Coram nurses locally and nationally.

Nutrition Super Power: Simplifying the care and maintenance of IV access catheters

Crystal Lee Wilkinson, PharmD, RPh
Clinical Pharmacist, Coram TPN Excellence Team
Coram CVS/Specialty Infusion Services
Crystal has been a practicing pharmacist for 12 years, with Coram for 8. She is licensed in California and Missouri and based in San Diego.
Nutrition Super Power: Helping to ease patients and caregivers’ anxieties around TPN at home upon discharge from hospital.

Thank you to our sponsor!

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