presents
Fort Lauderdale, Florida Regional Conference

November 9, 2019
9:30 am – 5:15 pm

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<th>Time</th>
<th>Event</th>
<th>Speaker(s)</th>
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<td>9:30 a.m.</td>
<td>Introduction</td>
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<td>9:40 a.m.</td>
<td>Consumer Story</td>
<td>Alison Beckwith</td>
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<td>10:00 a.m.</td>
<td>Normalizing Life on Therapy</td>
<td>Madalyn George-Thiemann, RN, CNS; Edmarc Hospice for Children</td>
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<td>10:30 a.m.</td>
<td>New Updates on Pediatric Intestinal Rehabilitation</td>
<td>Debora Duro, MD, MS, Program Director, Pediatric Gastroenterology, Hepatology and Nutrition and Medical Director of “FIRST “- Florida Intestinal Rehabilitation, Support and Treatment Program</td>
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<td>11:00 a.m.</td>
<td>Break</td>
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<td>11:15 a.m.</td>
<td>Short Bowel Syndrome: How to Eat When You Can’t Eat</td>
<td>Laura Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN, Professor, East Carolina University</td>
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<td>11:45 a.m.</td>
<td>Questions for the morning panel</td>
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<td>12:15 p.m.</td>
<td>Lunch and Networking</td>
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<td>1:30 p.m.</td>
<td>The Role of Teduglutide in Weaning Parenteral Support in Patients with Short Bowel Syndrome</td>
<td>Andrew Ukleja, MD, AGAF, CNSP; Gastroenterology Clinic, BIDMC</td>
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Round Table Session #1 - 2:00 p.m.-2:45 p.m. & 2:45 p.m.-3:30 p.m. (choose 2 round tables)

- **Tube Feeding Complications** - Amanda Gilhool, MS, RD, LD/N, CNSC; Jackson Memorial Hospital
- **CLABSI Prevention: Update On Best Practice** - Kristi Griggs, RN, CNSC; Nutrition Nurse Manager, ThriveRx
- **Ostomy/Stoma Care: Problems and Solutions** - Anita Prinz, RN, MSN, CWOCN; Private Nursing Consulting services
- **Pediatric Blenderized Tube Feeding (2:45 p.m. - 3:30 p.m. ONLY)** - Sonia Motolongo RD, LD/N, RN, IBCLC & Cristhiane Schneider Santos, MS, RDN, LN; Broward Health/ Broward Health Medical Center

3:30 p.m. Break - Oley Raffle

Round Table Session #2 - 3:45 p.m.-4:30 p.m. & 4:30 p.m.-5:15 p.m. (choose 2 round tables)

- **Lipid Management in Parenteral Nutrition** - Kathleen Crim, MS, RD, LD/N, CNSC; Dietitian
- **Living Life to the Fullest (traveling)** - Lynn Wolfson, MBA, Ed.S.; HPN Consumer; TSA Supervisor Naomi Allen & TSA Officer Elbiatriz Davila
- **ENFit- Navigating Enteral Tube and Supply Changes** - Erin Kerrigan, MS, RDN, CNSC; Mayo Clinic
Swimming and HPEN - Denise Richardson, RN, CNSC; National Pediatric Nurse Specialist, Nutrishare

Pediatric Blenderized Tube Feeding (3:45 p.m. - 5:15 p.m. ONLY) - Sonia Motolongo RD, LD/N, RN, IBCLC & Cristhiane Schneider Santos, MS, RDN, LN; Broward Health/ Broward Health Medical Center
Our Speakers

Alison Beckwith, caregiver
Fort Worth, Texas

Ali has two children, Alex and Madelyn, with mitochondrial disease. Alex has an ileostomy and has been on parenteral and enteral nutrition since 2008. Madelyn is on enteral nutrition. Ali and Alex are ambassadors for the Children’s Miracle Network Hospitals. Ali is also on their hospital’s family advisory and CLABSI councils.

Kathleen Crim, MS, RD, LD/N, CNSC
Miami, Florida

Kathleen has worked as a registered dietitian and certified nutrition support clinician. She most recently managed the home parenteral nutrition program at Miami Transplant Institute. She oversaw all patients on TPN that are part of the intestine and multivisceral transplant programs as well as intestinal rehabilitation program. She has worked as a clinical dietitian with a focus on critical care and acute nutrition at Northside Hospital as well as a clinical dietitian with a focus on trauma/surgical critical care at Grady Memorial Hospital. Prior to working in the clinical setting, she worked as a wellness resource specialist for Morrison Management Specialists where she developed and implemented wellness programs for hospital associates. She currently is a board member for the Georgia chapter of ASPEN.

Debora Duro, MD, MS
Florida Intestinal Rehabilitation, Support and Treatment Program “FIRST”
Fort Lauderdale, Florida

Dr. Debora Duro is the Program Director of Pediatric Gastroenterology, Hepatology and Nutrition and Medical Director “FIRST for Children” (Florida Intestinal Rehabilitation Support and Treatment) Program at Salah Foundation Children’s Hospital at Broward Health Medical Center in Ft Lauderdale, FL, USA. Appointed in 2015, she brings extensive experience in treating children suffering from Intestinal Failure and Short Bowel Syndrome. She is specialized in Nutrition Support and Home Parenteral Nutrition. She obtained her clinical fellowship in Pediatric Gastroenterology, Hepatology and Nutrition at Boston Children Hospital and Massachusetts General Hospital, both affiliated with Harvard Medical School, Boston, MA. At Boston Children’s Hospital Dr Duro worked at the CAIR (Center of Advanced Intestinal Rehabilitation) as an attending specialized in the care of children undergoing Intestinal Rehabilitation. She also has a Master of Science degree in Dietetics and Nutrition at Florida International University, Miami, FL. She has published many articles especially in the field of Intestinal Failure and Nutrition Support and currently holds an appointment as an Associate Professor in Clinical Pediatrics at Florida International University and Nova Southeastern University.

Dr. Duro is a member of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN); she is part of the Nutrition and Intestinal Rehabilitation Committees for NASPGHAN. And she is also a member of the American Gastroenterology Association (AGA) and active member at the American Society for Parenteral and Enteral Nutrition (ASPEN).

Statement: I am passionate about the field of Intestinal rehabilitation which I trained and learned at Boston Children Hospital, Harvard Medical School. Intestinal Rehabilitation is the first line treatment for kids suffering with Intestinal Failure and Short Bowel Syndrome. Long term parenteral nutrition is the long term treatment for children suffering from Intestinal Failure and nowadays it provides a great quality of life comparing to transplant and should be present as a FIRST option always to parents.
Madalyn George-Thiemann, RN, CNS
Edmarc Hospice
Chesapeake, Virginia

Madalyn is a Clinical Nurse Specialist with a degree from Syracuse University. With 51 years of pediatric nursing experience she is currently caring for children and their families at Edmarc Hospice for Children in southeastern Virginia. Many years ago, while practicing on the Pediatric unit of her hospital, she encountered an adorable toddler who needed a home and a loving mother to care and advocate for him as he navigated life with a high tech medical condition. Through many years of navigating his ups and downs her son is a productive young adult.

Amanda Gilhool, MS, RD, LD/N, CNSC
Jackson Memorial Hospital
Jacksonville, Florida

Amanda Gilhool, MS, RD, LD/N, CNSC is a clinical dietitian at Jackson Memorial Hospital, working with both medical ICU and liver transplant patients. Originally from Philadelphia, she earned her Bachelor’s degree from Temple University and her Master’s degree in Human Nutrition from Drexel University. Since coming to Florida in 2013, she has worked at hospitals in the Tampa Bay and greater Miami area. She has also been part of several ASPEN committees since becoming certified in nutrition support. Amanda is also expanding her private practice working with clients on tube feeding in an effort to help clients disconnect from their tubes and reconnect with their lives. When not in the hospital or focusing on her clients, she enjoys volunteering, listening to podcasts, doing trivia, and playing kickball terribly.

Kristi Griggs, RN, CNSC
ThriveRX

Kristi has 23 years experience as a registered nurse with the last 17 of these years in home nutrition support. Kristi has been a part of the ThriveRx team since 2012 and her areas of clinical interest are disorders of mitochondrial metabolism and the medically fragile pediatric population. Kristi holds national certification in nutrition support.

Erin Kerrigan, MS, RDN, CNSC
Mayo Clinic
Jacksonville, Florida

Erin Kerrigan is a Registered Dietitian Nutritionist with a Master’s Degree in Nutrition from the University of North Florida. As a certified nutrition support clinician with almost 15 years’ experience, she has worked with pediatric and adult patients who depend on tube feeding or IV nutrition. Her career has allowed her to place feeding tubes, be an early adopter of ASPENs malnutrition criteria, manage home parenteral nutrition, educate the next generation of clinicians and maintain a strong advocacy for her patients. Erin is currently a Nutrition Support Dietitian at Mayo Clinic Jacksonville and is a Clinical Instructor for the Mayo College of Medicine.

Laura Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN, FAND
Brody School of Medicine, East Carolina University
Greenville, North Carolina

Dr. Laura Matarese is Professor Of Medicine and Surgery at The Brody School of Medicine at East Carolina University in Greenville, North Carolina. She is the author of over 250 publications including books, chapters, manuscripts, and abstracts and currently serves on the editorial boards of several journals. She has lectured extensively, both
nationally and internationally and has held numerous positions within the American Society for Parenteral and Enteral Nutrition, the Academy of Nutrition and Dietetics and the Commission on Dietetic Registration. Prior to her matriculation to ECU she worked at the Starzl Transplant Institute at the University of Pittsburgh and the Cleveland Clinic. She holds a PhD in nutrition from Rutgers University.

**Sonia Motolongo, RD, LD/N, RN, IBCLC**  
Broward Health/Broward Medical Center  
Fort Lauderdale, Florida

Sonia is a Medical Doctor from Venezuela. RN, IBCLC and Clinical Pediatric Dietitian (graduated in Southeast Missouri State University), with more than 20 years of experience working in Pediatric Nutrition. She is the clinical Pediatric Dietitian at Salah’s Foundation Children Hospital, Broward Health Medical Center, Fort Lauderdale, Florida and she is also part of the Outpatient Blenderized-Feeding clinic program.

**Anita Prinz, RN, MSN, CWOCN**  
Fort Lauderdale, Florida

Anita joined the nursing profession in 1995 after a career in fashion. She quickly found her niche in the wound, ostomy, and continence specialty and became certified in 2001. Thirsty for more knowledge, she obtained a master’s degree in Nursing in 2009. Anita has served on several committees for the WOCN Society and is the lead author of their Best Practice Guideline for Ostomy Discharge Planning. She is currently on the Advocacy Board for the United Ostomy Association and is a strong proponent for the ostomy patient’s Bill of Rights. Anita has written many articles on ostomy care for The Phoenix and is currently the “Ask the Ostomy Nurse” author. She is in private practice and is passionate about the prehabilitation and rehabilitation of the ostomy patient.

**Denise Richardson RN, CNSC**  
Nutrishare  
Elk Grove, California

Denise has been a leader in the field of Nutrition Support for over 30 years. She was the Nutrition Support Nurse Coordinator at Boston Children’s Hospital from 1983 through 2013. During her tenure at the hospital, she developed nursing policies and procedures and lectured throughout the institution to all disciplines about a variety of nutrition support topics. She helped transition hundreds of children from hospital to home, while ensuring the quality of the homecare pharmacies and nursing agencies providing care to these families.

She has published numerous articles and written book chapters regarding Home Parenteral Nutrition. She is an active participant in the American Society for Parenteral and Enteral Nutrition (ASPEN) where she has participated in task forces to publish standards of care for nurses in the field and standards for PN administration.

Since 2012 Denise has worked for Nutrishare, Inc a specialty pharmacy as their National Pediatric Nurse Specialist.

**Cristhiane Schneider Santos, MS, RDN, LN**  
Broward Health/Broward Health Medical Center  
Fort Lauderdale, Florida

She is a Registered Dietitian with a Master’s Degree in Clinical Nutrition from Florida International University. Cristhiane has been working as a Registered Dietitian for almost 15 years. She is currently working as a NICU Dietitian
and part of the team of Outpatient Blenderized-Feeding Clinic at Salah’s Foundation Children Hospital in Broward Health Medical Center. Fort Lauderdale, Florida

Andrew Ukleja, MD, AGAF, CNSP
Beth Israel Deaconess Medical Center
Boston, Massachusetts

Dr. Andrew Ukleja has been a Gastroenterologist at Beth Israel Deaconess Medical Center (BIDMC) in Boston since 2018, where he joined the GI faculty as a Lecturer in Medicine, Harvard Medical School. He finished his fellowship in Gastroenterology at Mayo Clinic Jacksonville, Florida. He was previously on GI Staff in the Department of Gastroenterology at Cleveland Clinic Florida, Weston for almost 17 years, serving as a Director of the Nutrition Support Team and also running an intestinal failure program. He had prior appointments as an Affiliate Assistant Professor of Medicine at Florida Atlantic University, Boca Raton; Assistant Professor of Medicine at University of South Florida, Tampa; Clinical Assistant Professor of Medicine Cleveland Clinic Lerner College of Medicine of Case Western Reserve University, Cleveland; and Affiliate Associate Professor of Medicine St. George’s University School of Medicine, Grenada.

Dr. Ukleja has developed a regional and national reputation based on his superior management of patients with malnutrition and short bowel syndrome-intestinal failure. He has published a number of research papers, reviews, and chapters on this topic, and he has held leadership positions in the American Society for Parenteral and Enteral Nutrition.

He is a long-standing member of the European Society of Parenteral and Enteral Nutrition and the American Society of Parenteral and Enteral Nutrition. In the past, he served as the President of Florida Society for Parenteral and Enteral Nutrition and Chairman of the By-Laws Committee for Florida Gastroenterological Society. Since arriving at BIDMC, Dr. Ukleja has developed a robust referral practice of patients with various forms of malnutrition secondary to chronic GI diseases. His special areas of interest include: enteral and parenteral nutrition, short bowel syndrome, gastrointestinal dysmotility, obesity, and celiac disease.

Dr. Ukleja has published more than 40 scholarly articles in the peer-reviewed GI literature. Most of his publications are focused on his areas of clinical expertise: gastroparesis, intestinal failure and nutritional support. Dr. Ukleja has been invited frequently to deliver scholarly lectures and organized seminars on these highly-specialized GI topics. Based on his clinical expertise, he is a frequent reviewer for peer-reviewed specialty journals and has been invited to serve on the editorial boards of several international GI journals. He was a special guest editor for an issue of Gastroenterology Clinics of North America dedicated to nutritional management of gastrointestinal diseases.

Lynn Wolfson, MBA, Ed.S.
HPN Consumer, Oley Ambassador, South Florida Ostomy and Tube Feeding/HPN Support Group
Weston, Florida

Lynn was born in New Jersey in 1959 with Hirschsprung’s Disease which severely affects the functioning of the digestive system. She has a permanent ileostomy, a gastrostomy and a Hickman for TPN. In addition, she needs to catheterize six times a day.

Lynn has a service dog named, Zev, who does not miss a meeting! He was trained by a service animal trainer for her specific needs. Zev is always with Lynn and he has traveled throughout the USA and Canada.
Lynn enjoys traveling with her husband and family. She has traveled to Europe, Russia, the Middle East, Africa, Japan, Hong Kong, Macau, Viet Nam, Cambodia, Thailand, Singapore, Australia, Central America, Mexico, the Caribbean, Canada and to 43 states.

She is married to Eli Wolfson for 33 years and they have two daughters who are both biomedical engineers. One of their two daughters is also a physician and is doing her residency at Baylor. Lynn has a Master in Business Administration, a Post-Master in Computer Systems and an Educational Specialist Degree in Mathematics Education. She was a corporate executive for Burdines for 9 years and taught in Dade and Broward County schools for 16 years as a Middle and High School Science and Math Teacher.

Lynn Wolfson is the Founder and President of The South Florida Ostomy and Tube Feeding/HPN Support Group in Weston, Florida which meets the third Tuesday of each month at 6:00 p.m. at Delvecchio’s in The Weston Town Center.

Lynn’s goal in life is to live life to the fullest by being a functioning family member and contributing to her community through touching each individual she meets in a positive way so they can appreciate the gifts life has given them and contribute positively to society.
A Special Thank You To

Our Speakers for taking time out of their busy schedules to share their expertise with us.

Our co-sponsors for generously supporting this regional conference.

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To all our attendees, thank you for coming and we hope to see you at another Oley conference. Safe travels!

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