11:00 AM – Introductions

11:15 AM – Living with SBS into Adulthood: My Journey to Respect Health and Life – Swapna Kakani, Professional Speaker, Healthcare Advocate

11:35 AM – Avoiding Complications of HPN – Vanessa Kumpf, PharmD, BCNSP, FASPEN; Clinical Pharmacist Specialist, Vanderbilt University Medical Center

12:10 PM – Oley Foundation and ASPEN: Partners in Advocacy – Penny L. Allen, RD, CNSC, FASPEN; National Director, Nutrition Support, Optum Infusion Pharmacy; Bettemarie Bond OTR/L; Oley Ambassador

12:45 PM – 10 minute break

12:55 PM – Choosing the Right Tube – Sara Seegmiller, RN, BSN, Home Enteral Nutrition Team Instructor in Nursing, Mayo Clinic College of Medicine, General Internal Medicine

1:30 PM – Sponsor coordinated session with Takeda
   Learn about Gattex from Ann Michalek, MD, Associate Professor of Clinical Medicine, Albany Medical Center. This program is intended for patients and caregivers of patients 1 year of age and older with short bowel syndrome (SBS) who are dependent on parenteral support (PS).

2:00 PM – Sponsor coordinated session with Optum Infusion Pharmacy
   Join us to learn more about a short bowel syndrome (SBS) consumer’s PN independence journey using Optum’s Intestinal Rehab program. During this interactive session, you will hear from both the consumer and clinician as they discuss the benefits of a home-based intestinal rehab program. The program brought to you by Optum Infusion Pharmacy helps you achieve your goals in reducing the need for parenteral nutrition therapy and intravenous fluids.

2:30 PM – Rashes and Splashes: Care of Peri Ostomy and Feeding Tube Skin – Susan Hamilton, RN, MS, CCRN, CWOCN; Pediatric Critical Care Nurse Practice Specialist, Boston Children’s Hospital

3:05 PM – 10 minute break

3:15 PM – Standing Tall in the Face of Adversity: The Power of Wellness-Enhancing Practices – Saundra Jain, MA, PsyD, LPC; Individual & Family Counseling, Adjunct Clinical Affiliate, School of Nursing at University of Texas at Austin

3:50 PM - Closing Remarks
Our Speakers

Penny Allen, RD, CNSC, FASPEN  
National Director, Nutrition Support  
Optum Infusion Pharmacy  
North Hampton, New Hampshire

Penny Allen, RD, CNSC, FASPEN is the National Director of Nutrition Support for Optum Infusion Pharmacy, formerly known as BriovaRx Infusion. Penny has been in the HPN/home infusion industry for over 30 years, starting her nutrition career at Beth Israel Hospital in Boston, MA. She is a Certified Nutrition Support Clinician, serves as Chair of the A.S.P.E.N. Public Policy Committee, is a published subject matter expert in Medicare PN policy and has had the good fortune and honor of working with the Oley Foundation for greater than 25 years.

Bettemarie Bond, OTR/L  
Oley Ambassador  
Levittown, Pennsylvania

With a diagnosis of Mitochondrial Myopathy, BetteMarie has been an Oley Ambassador since 1992. Bettemarie has gained her independence while on HPN, hydration therapy and PCA. She went to college, graduated, worked for fourteen years, and purchased her own home—all while connected around the clock to an IV infusion. For years Bettemarie has lobbied on Capitol Hill for various issues, and has done advocacy work with patient organizations including DDNC, MDA, UMDF, and more. She is the first person on TPN who is a member of ASPEN’s Public Policy Committee. Her positive perspective, kindness, generosity, and “can do” attitude set a terrific example of what can be achieved while on therapy.

Susan Hamilton, RN, MS, CCRN, CWOCN  
Pediatric Critical Care Nurse Practice Specialist  
Boston Children’s Hospital  
Boston, Massachusetts

Nurse Practice Specialist in Pediatric ICU at Boston Children’s Hospital. I am a certified wound, ostomy, continence nurse and I am the Co-Chair of the Skin Committee at BCH. I have spoken nationally about pressure injury prevention in critically ill children. I also have an interest in pediatric critical care nutrition and have published several articles about using an enteral nutrition algorithm to improve nutrition outcomes in the Pediatric ICU.

Saundra Jain, MA, PsyD, LPC  
Psychotherapist; Individual and Family Counseling  
Austin, Texas

Saundra Jain, MA, PsyD, LPC, is an Adjunct Clinical Affiliate, School of Nursing, at The University of Texas at Austin. She is focused on wellness and the impact of positive psychology on client outcomes. Her research explores the connection between wellness and its anti-inflammatory effects, as well as improvement in disease and wellness markers. She is also researching the intersect between psychedelics and wellness. In
1992, she launched a private practice of psychotherapy where she currently provides services for a wide range of mental health issues.

Dr. Jain is a co-creator of the WILD 5 Wellness Program, which combines five elements of wellness (exercise, mindfulness, sleep, social connectedness, and nutrition) along with positive psychology practices into a prescriptive, simple wellness program. She is co-author of two well-received workbooks written for those interested in improving their mental wellness - KickStart30: A Proven 30-Day Mental Wellness Program and LiveWell90: A Proven 90-Day Mental Wellness Program. She is also co-author of The Science and Practice of Wellness: Interventions for Happiness, Enthusiasm, Resilience, and Optimism (HERO), which was recently published by Norton Publishing (2020).

Dr. Jain is active in peer-to-peer education especially in the disease states of depression, anxiety disorders, and ADHD. Another strong clinical and educational interest involves differential diagnosis of major psychiatric disorders. She is co-creator of an educational initiative exploring the mind-body connection between rheumatology and mental health. Dr. Jain’s educational initiatives have reached both domestic and international audiences. She serves as a member of the Psych Congress Steering Committee providing direction regarding educational gaps/needs for healthcare practitioners in the world of mental health.

Swapna Kakani
Professional Speaker, Healthcare Advocate
Huntsville, Alabama

Swapna Kakani is a sought-after professional speaker in the area of overcoming personal adversity, and an advocate in the area of healthcare delivery and the patient experience. Her inspirational life story shows audiences her individual resilience and self-determination in the face of constant difficulties, as well as the impact her healthcare advocacy has across disciplines. Swapna was diagnosed with Short Bowel Syndrome at birth due to atresia and for 31 years has lived with supplemental intravenous nutrition and a feeding tube for 24 years. In 2014, she had a small intestine organ transplant. Swapna through her platform, Swapna Speaks, has given several presentations across the world to various healthcare companies and associations, hospitals, and non-profit events, including the Cleveland Clinic/HIMSS Patient Experience Summit, and a TEDx talk in 2017. Swapna, does healthcare advocacy work both at the federal and state level for the Short Bowel Syndrome/Intestinal Failure and broader rare disease community. She has been part of various projects to improve care and maintenance for IV and enteral nutrition consumers and part of policy and regulation changes to improve the rare disease patient experience. In 2017, she founded Alabama Rare, a grassroots coalition to unite the state around the rare disease population. It acts to bring support for individuals & families, educate the broader community, bring awareness to the population’s needs, and advocate for necessary change. Swapna on behalf of Alabama Rare, was instrumental in creating the Alabama Rare Disease Advisory Council and an annual statewide rare disease symposium. She now is the EveryLife Foundation RDLA State Advocacy Fellow creating their state policy and advocacy program using what she has learned from forming Alabama Rare.

In March 2019, Swapna was awarded the consumer advocacy award by the American Society for Parenteral and Enteral Nutrition, and in July 2019, was nominated by Wego Health as a patient leader hero. In August 2020, she was awarded the Innovator/Advocate Award by the Oley Foundation. You can follow Swapna on Facebook, Twitter, and Instagram @SwapnaSpeaks.

Swapna is originally from Huntsville, AL, received her bachelors in Psychology and Master’s in Public Health from the University of Alabama at Birmingham (UAB).
Maria Karimbakas, R.D., CNSC  
Clinical Dietitian  
Optum Infusion Pharmacy

Maria Karimbakas is a registered dietitian and board certified in nutrition support, who received her Bachelor of Science from the University of Vermont and completed her dietetic internship at Brigham and Women’s Hospital, Boston. She has been providing clinical care and education to short bowel consumers for over 20 years and worked at the Nutritional Restart Center, the first intestinal rehabilitation program. Maria has co-authored several abstracts, papers, and book chapters on the subject of diet and SBS and is the co-author of ThriveRx’s Maximize Health Home Intestinal Rehabilitation program.

Vanessa Kumpf, PharmD, BCNSP, FASPEN  
Clinical Pharmacist Specialist  
Vanderbilt University Medical Center  
Nashville, Tennessee

Vanessa Kumpf is a Nutrition Support Pharmacy Specialist at the Center for Human Nutrition at Vanderbilt University Medical Center in Nashville, Tennessee. She has extensive experience working as a clinical pharmacy specialist in the area of nutrition support in hospital, home care, and outpatient settings. Her current practice site focuses on the outpatient management of adult patients with intestinal failure.

Ann Michalek, MD  
Albany Medical Center  
Albany, New York

Dr. Michalek specializes in clinical nutrition at Albany Medical Center. She completed her fellowship with Oley’s co-founder, Lyn Howard, MD, and assumed responsibility for many of Dr. Howard’s patient’s when Dr. Howard retired in 2007.

Sara Seegmiller, RN, BSN  
Home Enteral Nutrition Team  
Instructor in Nursing  
Mayo Clinic College of Medicine, General Internal Medicine  
Rochester, Minnesota

Sara Seegmiller graduated from Rochester Community and Technical College in 1994, with an Associated Degree in Nursing. She then graduated from Winona State University in 1998, with a Bachelors degree in Nursing. She has currently finished all classes, and working on competing her thesis, for her Masters of Arts in Nursing degree from Augsburg University. Sara worked in the emergency department at Olmsted Medical Center in Rochester for 13 years. She started at Mayo Clinic in 2008, in Gastroenterology and Hepatology (GI). She quickly worked her way through various procedures and became the second RN to place percutaneous tubes for GI. The nurses who place tubes are called ‘PEG nurses’. She placed PEG and PEJ tubes for 6 years in GI. In 2013, she helped develop the nursing role in the Home Enteral Nutrition Clinic, or HEN clinic. At that time, she transitioned to General Internal Medicine (GIM).

She is still currently a nurse in GIM. Currently she is one of four nurses who works in the HEN clinic. The nurses in the HEN clinic see all adult patients who have a tube placed as an outpatient in GI or Interventional
Radiology (IR), before and after procedures, before their first tube replacement, before removal and any time there is a problem, question or concern with the tube or site. In 2019, we had 1253 nurse visits. The nurses are also responsible for scheduling all adult outpatient tube procedures, 1200-1500 a year. We also take care of all adult outpatient calls and messages from patients on concerns or issues with tubes.

She also has very active roles in GIM, as chair of the Unit Coordinating Council (for nursing) and sits on GIM’s Diversity, Equity and Inclusion Committee (as a nursing representative). She also actively participates in ongoing research projects with the HEN clinic. She has done several presentations on the HEN clinic and feeding tubes, at both state and national conferences.
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Takeda seeks to transform the outlook of patients living with rare and hard to treat gastrointestinal conditions by helping to address unmet needs. For more than ten years Shire has made a commitment to the GI community, and the company aims to extend its GI portfolio to new indications and therapeutic areas.