

We strongly advise that you **discuss with your physician any medical information** received from the Oley Foundation through conference presentations, informal discussions, the newsletter, etc.—before you make any changes in your health care.

We do our best to offer **a selection of foods that we hope will meet your dietary issues**. If you have a specific need, please inform Cathy at registration and we'll try to help.

Smile! You're on Camera!

Oley and its sponsors will be taking photos and videotaping in the conference sessions and events. These images may be used by the sponsor or Oley, online or in promotional materials, without further agreement. **If you do not want your photo used**, please let us know and we will do our best to honor your wishes. We can't guarantee that your image won't appear in group shots or on the video filmed at the conference. To "opt out," **please sign a release at the registration table**, or e-mail your name and an image (so we can identify you) to Lisa Metzger at metzgel@mail.amc.edu.



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Albany Medical Center, MC-28
Albany, NY 12208-3478
(800) 776-OLEY, (518) 262-5079, FAX (518) 262-5528
BishopJ@mail.amc.edu
www.oley.org

Welcome!

Welcome to Orlando, “The City Beautiful,” and to “Help Along the Way,” the 29th Annual Oley Foundation Consumer/Clinician Conference. Last year, in Hyannis, Massachusetts, a wonderful time was enjoyed by all. We hope this year’s conference will be just as enjoyable, if not better!

As we gather here in Orlando there will be moments of fun and relaxation, time to learn about advances in therapy and research, a chance to hear about new products/equipment, and learn from consumers and top healthcare professionals, and—best of all—TIME to reunite with old friends and meet new ones! From the Welcome Reception and Talent Show to the main sessions, the Tube Feeding Workshop, the breakout sessions Tuesday and Wednesday, the exhibit area, Jammin’ Jammies, and the silent auction and picnic, there is plenty of opportunity to learn and socialize.

We hope that while you are here in Orlando you will have time to visit some of the attractions that Orlando and the rest of Florida have to offer. Of course there are Sea World, Disney World, and Universal Studios in the immediate area. There is also Busch Gardens in Tampa, Legoland near Winter Haven, and the Kennedy Space Center in Titusville. There are many natural attractions, and it’s a short drive to the Atlantic beaches of Cocoa Beach and Daytona Beach to the east, and the Gulf beaches of St. Petersburg/Clearwater Beach to the west. There are also many wonderful restaurants and other attractions (both indoor and outdoor) here in the Orlando area as well.



We are happy you are here with us and hope that your experience is both rewarding and enjoyable.

Paula Johns, RN, MSN
Conference Co-chair

Mary and Bob Smithers
Conference Co-chairs

Oley Trustees & Staff

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Caregiver
Maple Grove, MN

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Marion Winkler, PhD, RD, LDN, CNSC

Rhode Island Hospital
Providence, RI

Lyn Howard, MB, FRCP, FACP, Medical Director, Co-Founder

Albany, NY

To learn more about the role of Oley Foundation trustees, and/or to submit a name for consideration by the Oley Board of Trustees Nomination Committee, contact Joan Bishop (800-776-OLEY / bishopj@mail.amc.edu).

Staff:

Joan Bishop, Executive Director

bishopj@mail.amc.edu

Celebrating thirty years with Oley in 2014, Joan handles the multitude of tasks it takes to keep Oley running and growing, including budget planning, building relationships, advocacy efforts, fundraising, board development, coordinating the annual conference, etc. She is dedicated to fulfilling the Foundation's mission and welcomes your ideas, comments, and criticisms.

Roslyn Dahl, Communications & Development Director

dahlr@mail.amc.edu

Roslyn is responsible for raising funds for the Foundation as well as producing Oley publications, coordinating online education programs, managing Oley's Web page content and information clearinghouse. Call on her to research your questions or to share ideas for Oley publications (other than the newsletter) or promotions.

Andrea Guidi, Executive Assistant

andreaguidi.oley@gmail.com

Andrea joined Oley in 2013 and has been leading our efforts to upgrade the Oley Web site. Andrea got her start in nutrition with an undergraduate degree at the State University of New York and a dietetic internship at Sage Graduate School. She's provided supervision, nutrition education, and care planning in retirement and nursing home communities.

Cathy Harrington, Administrative Assistant

harrinc@mail.amc.edu

Cathy is the centerpiece of Oley efforts, managing the member database, answering most of your calls, and meeting the needs of the Foundation office. She is the glue that holds us together! She has experience in patient care and extensive knowledge of the nutrition support arena.

Darlene Kelly, MD, PhD, FACP, Science & Medicine Advisor

After retiring from her role as Medical Director for Home Parenteral Nutrition at the Mayo Clinic in Rochester, Minnesota, in 2012, Dr. Kelly agreed to serve as the Science and Medicine Advisor for Oley. As such she guides Oley research projects, provides advice on medical-related content for publications, and has worked with Joan Bishop on drug shortage efforts and on educational issues for physicians and patients. Previously she supported Oley as a board member and research committee chair for more than eleven years.

Lisa Metzger, Editor, *LifelineLetter*, Director, Community Engagement

metzgel@mail.amc.edu

Lisa has been the editor of the *LifelineLetter* since 2007. She has been a member of Oley for many years following her two stints on HPN due to hyperemesis gravidarum while pregnant. Lisa's responsibilities at Oley also include advocacy and outreach efforts. She welcomes your ideas and articles for the newsletter, and input on outreach.

General Information

Registration and Conference Information

Information about all aspects of the conference is available at the registration desk. The desk will be staffed Monday 1:00 p.m. to 5:00 p.m., Tuesday 8:00 a.m. to 4:45 p.m., and Wednesday 8:00 a.m. to 4:45 p.m. All conference activities will be held at the Renaissance. A map of the meeting rooms is on the back cover of this program.

Medical Support/Emergency Services

For an emergency: Contact your primary care physician (if time allows) to discuss the proper treatment plan prior to going to a medical center. The following hospital has been alerted as to the increased potential for a GI or HPEN incident, and is prepared to meet your needs:

Adults: Orlando Regional Medical Center, 1414 Kuhl Ave, Orlando, FL 32806; (407) 649-9111

Pediatrics: Arnold Palmer Children's Hospital, 92 West Miller St, Orlando, FL 32806; (352) 294-5252

Telephonic support/backup for (emergency) nursing and pharmacy infusion services during the conference has been graciously offered by Coram Specialty Infusion Services. Call the Tampa Coram branch at 813-639-4500 (24 hour availability) and identify yourself as an Oley Conference participant. They will need contact information for your physician in order to obtain orders. They can dispense prescribed fluids, additives, and supplies with a physician's order. They can also help troubleshoot a consumer's pump, provided it is one with which they are familiar.

Video Testimonials

Has Oley had an impact on you? Sharing your stories is an important way to keep Oley moving forward. Ask at Oley registration for the location and time. Thank you!

Ambassador Workshop/Volunteer Info Session

Planned for "official" Oley volunteers, but **open to everyone** with an interest in serving Oley via networking, social media, marketing, graphic design, etc. Meet us in the Coral Ballroom, Monday at 1 p.m.

First-Time Conference Attendee Orientation

Hosted by Nutrishare, Inc., this session is a must attend for first-time Oley Conference goers. Meet Oley staff Monday at 6:00 p.m. in Odyssey to learn how to make the most of your first conference experience.

Welcome Reception/Awards Ceremony

We kick off the meeting Monday at 7:00 p.m. in the Coral Ballroom. We'll celebrate Oley Annual Awards recipients, enjoy a talent show, and connect with old friends and meet new ones. Dessert-type refreshments will be served.

Continental Breakfast

Tuesday and Wednesday, attendees are encouraged to start their day with a delicious selection of breakfast foods. A buffet will be set up in the Atrium near the exhibits. Hosted by Walgreens Infusion Services on Tuesday.

Exhibit Hall

Come learn about parenteral and enteral products and services, Tuesday and Wednesday, in the Atrium 8:00 to 9:00 a.m., and noon to 2 p.m. Complimentary lunch will be served both days. **Don't miss the exhibits on both sides of the atrium.**

New this year: Consumers, family members, and faculty 16+ years of age are encouraged to complete an **Exhibitor Score Card** for a chance to win a \$200 gift card! Many of the vendors will also have raffle contests to enter. Drawings will be held at 1:30 p.m. on Wednesday; you must be present to win!



Rehydration Station

Stop by the Rehydration Station Tuesday and Wednesday, 8:00 to 9:00 a.m., and noon to 2 p.m., and Thursday morning before the walk-a-thon, to sample oral rehydration solutions and learn how they might benefit you. Thanks to ThriveRx for sponsoring the station, and to Cera Products and Jianis Brothers for donating product samples.

Child Care—Labrid A & B

Tuesday & Wednesday, 9 a.m.–noon, and 2:00–4:30 p.m.

Pre-registration required. All children's items should be labeled.

Please pay particular attention to the special needs portion of the permission slip. It will be inserted into your child's name badge holder so this critical information will be with them as they travel to each activity. Children should be picked up promptly at noon and 4:30—even if the sessions haven't ended.

Tuesday, youth will enjoy games (including Wii and Xbox), puzzles and crafts. **Wednesday**, they will be decorating pillowcases.

Main Sessions

Tuesday:

- *Advocating for Yourself and/or Your Child*
- *"Stay Connected" as Enteral Tubes Roll Out!*
- *Swimming or Not?*

Plus, Hot Topics in Research

- *A Qualitative Study of the Perceived Value of Membership in the Oley Foundation by HPEN Consumers*
- *Successful Rehabilitation in Pediatric Ultrashort Small Bowel Syndrome*
- *A Cognitive Aid "Central Line Care Card" for Central Line Associated Bloodstream Infections in Pediatric HPN Patients*

Wednesday

- *New Treatment for Short Bowel Syndrome*
- *Growing New Bowel: The Future Cure for Short Bowel Syndrome*
- *Balancing HEN and HPN Therapies*
- *The Power of Social Media*
- *Strategies for Intestinal Rehabilitation*

Throughout the conference you'll see Oley volunteers designated with a hot melon colored ribbon. Be sure to thank them for helping to make this meeting a success.

General Info. (cont.)

Food Fun at Lunch

Registered Dietitians can make such a difference in your comfort and well-being by helping you understand what you can eat. The Oley conference offers you a great opportunity to talk with a dietitian at lunch. Look for a sign on the lunch tables, and ribbons that say “Ask Me, I’m a Dietitian.”

Volunteer dietitians include: Penny Allen, RD, CNSD; Elaine Arthur, RD, LD-NH, LDN; Charlene Compher, PhD, RD, FADA, CNSC, LDN; Carol Ireton-Jones, PhD, RDN, LD, CNSC, FASPEN; Laura Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN; Elizabeth Pash, MS, RD, LDN; Craig Petersen, RD, CNSD; Cynthia Reddick, RD, CNSC; and Marion Winkler, PhD, RD, LDN, CNSC, FASPEN.

Youth Activity—Crystal Ballroom E

Tuesday & Wednesday, 2:00–4:30 p.m.

Pre-registration required. All children’s items should be labeled.

Tuesday afternoon, youth will enjoy a magic show.

Wednesday afternoon, sponsored by Walgreens, will feature Noah’s Ark Animal Workshop where they will make their own stuffed animal, and a meet and greet with gators and a Ball Python from Gatorland.

Children should be picked up promptly at 4:30—even if the sessions haven’t ended.

Your Choice! Breakout Sessions or Workshop

Sponsored in part by Nestlé, the **Tube Feeding Workshop** will be held on Tuesday afternoon in Crystal Ballroom D. Topics covered include the new enteral connectors, formula medication compatibility, blenderized formula, as well as navigating complications like leaky tubes and skin care.

Alternatively, you can choose to participate in the small group discussion breakout sessions (see page 6 for breakout session topics). There are more breakout sessions on Wednesday afternoon (see page 7).

Oley Benefit Auction

The fun begins Tuesday at 7:30 p.m. when the bidding opens in the Discovery Ballroom. (See details on bidding/raffles below.) Drop off donated items at the registration desk before Tuesday afternoon. Visa, MasterCard, and American Express will be accepted, as well as cash and personal checks. While you are there, enjoy a relaxing chair massage courtesy of caregiver Lesley Marino. Thank you to Janet Platt for keeping us organized.

Jammin’ Jammies!

Sponsored by Abbott Nutrition, the party begins at 8:00 p.m. Wednesday in Odyssey A & B. A scavenger hunt followed by a DJ and Karaoke with games will make for a memorable evening! Signed permission required.

Oley Walk-a-Thon

Pick up a pledge sheet Monday through Wednesday, and join us on Thursday! All ages are welcome; the walk will be easy enough for everyone who wants to participate. Turn in your completed sheet and pick up your t-shirt at the Oley registration desk on Wednesday, or Thursday morning in the Atrium at 10:30 a.m. The walk begins in the Atrium at 11:00 a.m. by registration.

Oley Annual Picnic

We are keeping this activity on site for your convenience! Hosted by Fresenius Kabi USA, this fun filled event will begin Thursday afternoon at 11:30 a.m. (immediately following the Walk-a-thon) in the Atrium. We’ll enjoy picnic fare, relay races and plenty of time to enjoy all that the Renaissance has to offer. It’s a special time to connect with others who live similarly, expand your network of friends, have some of your lingering questions answered, etc. Do not be afraid to ask Oley staff to help you find what you’re looking for. We’ll see you there!

No-Host Farewell Breakfast

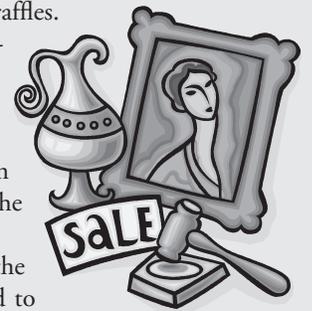
We’ll gather in the Trade Winds Restaurant, order off the menu, exchange parting wishes, and enjoy being surrounded by Oley attendees one last time before leaving for home. (Participants pay for their own breakfast.) To be included in this group please make your reservations by Wednesday at noon at Oley registration. Don’t forget your camera and address book!

Silent Auction Bidding and Raffle Policy

The silent auction and raffles are fundraising activities. Those held during the annual conference are to raise funds to offset conference expenses. Conference attendees, including Oley staff and Trustees, conference faculty, and the family members and friends thereof, are encouraged to participate in the silent auction and open raffles.

Items will be “sold” to the highest bidder at the closing of the event, or given to the winning ticket holder. (Note that these fundraising raffles are distinct from the raffles held by exhibitors in the Exhibit Hall.)

Consumer Only Raffle! In the spirit of the Oley conference and to enhance the experience for homePEN consumers, a raffle will be reserved for consumers only. A home enteral and/or parenteral consumer’s name must be designated on these tickets to be eligible to win. Good luck!!



Program

Monday

1:00 p.m. — 5:00 p.m.

Early Registration/Information
Atrium

1:00 p.m. — 6:00 p.m.

Ambassador Workshop/Volunteer Info Session
Coral Ballroom
See page 3 for details.

6:00 p.m. — 7:00 p.m.

First-Time Conference Attendee Orientation
Odyssey
See page 3 for details.

7:00 p.m. — 9:00 p.m.

Welcome Reception/Awards Ceremony/Talent Show
Coral Ballroom
See page 3 for details.

Tuesday

8:00 a.m. — 4:45 p.m.

Registration/Information
Atrium

8:00 a.m. — 9:00 a.m.

Exhibit Hall/Continental Breakfast
Atrium

9:00 a.m. — 11:45 a.m.

Main Session
Crystal Ballroom D & E

Advocating for Yourself and/or Your Child

Beth Gore, PhD, MBA

“Stay Connected” as Enteral Tubes Roll Out!

Peggi Guenter, PhD, RN

Swimming or Not?

Kathleen Gura, PharmD, BCNSP, FASHP, FPPAG



Please don't be late!

We have a packed agenda. Sessions will need to start on time.

Plus, Hot Topics in Research

** A Qualitative Study of the Perceived Value of Membership in the Oley Foundation by HPEN Consumers*

Katelyn Chopy, MS, RD, LDN

** Successful Rehabilitation in Pediatric Ultrashort Small Bowel Syndrome*

Brandi Gerhardt, RN, BAN

** A Cognitive Aid “Central Line Care Card” for Central Line Associated Bloodstream Infections in Pediatric HPN Patients*

Michelle Park, BA

11:45 a.m. — 12:00 p.m.

Oley Corporate Partner Awards
Crystal Ballroom D & E

12:00 p.m. — 2:00 p.m.

Exhibit Hall/Lunch
Atrium
Complimentary lunch served.

2:00 p.m. — 4:30 p.m.

Youth Activity
Crystal Ballroom E
See page 4 for details.

2:15 p.m. — 4:30 p.m.

Tube Feeding Workshop
Crystal Ballroom D

The Tube Feeding Journey: Avoiding/Navigating Complications

Mark H. DeLegge, MD

Understanding Upcoming Changes

Tom Hancock

Medication and Formula Compatibility

Michelle Romano, RD, LD/N, CNSC

Tips for DeClogging

Michelle Romano, RD, LD/N, CNSC

Know Your Formula, Know Your Food

Allison Thompson, RD

Program

2:15 p.m. — 3:15 p.m. Breakout Session I

3:30 p.m. — 4:30 p.m. Breakout Session II

(choose two)

- *Let's Discuss More About Swimming*
Kathleen Gura, PharmD, BCNSP, FASHP, FPPAG
Odyssey A
- *Communicating with Clinicians for Best Outcome*
Ann Weaver; Lyn Howard, MB, FRCP
Odyssey B
- *Session I only: Coping with HPN and Maintaining Normalcy* (Consumers only please)
Barbara Klingler
Atlantis A
- *Session II only: Coping with HPN and Maintaining Normalcy* (Spouse, adult caregivers only please)
Lee Klingler
Atlantis A
- *Nutrition Jeopardy*
Carol Ireton-Jones, PhD, RDN, LD, CNSC, FASPEN, FAN; Marion Winkler, PhD, RD, LDN, CNSC, FASPEN; Laura Matarese PhD, RD, LDN, CNSC, FADA, FASPEN; Fantail
- *Session I only: Bring Your Catheter Related Questions: Expertise Will Help*
Paula Johns, RN, MSN; Marianne Opilla, RN, BSN, CNSC
Cobia
- *Session II only: Prevent Infecting: Handwashing 101*
Paula Johns, RN, MSN; Marianne Opilla, RN, BSN, CNSC
Cobia
- *Session I only: New Lipids, Biologics, Triple Chamber Bags, etc.*
Penny Allen, RD, LD, CNSC
Bluegill
- *Session II only: Drug Shortages and Your HPN Bag*
Penny Allen, RD, LD, CNSC; Peggy Guenter, PhD, RN
Bluegill

- *Health Care Reform for the PN/EN Consumer/Parent*
Brenda Gray, PharmD, BCNSP, CNSC
Hinalea
- *Understanding Your Labs*
Deborah Pfister, MS, RD, CNSC
Koi
- *Avoiding HPN Related Liver Disease*
Reid Nishikawa, PharmD, BCNSP, FCSHP
Mako
- *Is Gattex for You?*
Kathryn Bundy; Ann Michalek, MD
Coral Ballroom A
- *Session I only: Understanding Gut Physiology*
Darlene Kelly, MD, PhD; Maria Karimbakas, RD, CNSC
Coral Ballroom B
- *Session II only: Getting Acquainted with What's in Your HPN*
Darlene Kelly, MD, PhD; Marianne Duda, MS, RDN, LD/N, CNSC
Coral Ballroom B
- *Ethanol Locks for Central Venous Access Devices*
Stephanie Pitts, MSN, RN, CPN, VA-BC
Coral Ballroom C
- *Session I only: Bacterial Overgrowth*
James Scolapio, MD
Atlantis B
- *Session II only: D Lactic Acidosis*
Craig Peterson, RD, CNSD
Atlantis B

7:30 p.m. — 9:00 p.m.

Oley Benefit Auction

Discovery Ballroom

See page 4 for details.

Please don't leave needles lying around in your hotel room. There will be a sharps container at the registration desk, if you didn't bring your own. Syringes without needles or blood can be disposed of in a non-see-through bag in the regular trash.



Program

Wednesday

8:00 a.m. — 4:45 p.m.

Registration/Information

Atrium

8:00 a.m. — 9:00 a.m.

Exhibit Hall/Continental Breakfast

Atrium

9:00 a.m. — 11:45 a.m.

Main Session

Crystal Ballroom D & E

New Treatment for Short Bowel Syndrome

Charlene Compher, PhD, RD, FADA, CNSC, LDN

Growing New Bowel: The Future Cure for Short Bowel Syndrome

Daniel H. Teitelbaum, MD

Balancing HEN & HPN Therapies

Arlet Kurkchubasche, MD, FACS, FAAP

The Power of Social Media

Michael Seres

Strategies for Intestinal Rehabilitation

Kishore Iyer, MBBS, FRCS, FACS

11:45 a.m. — 12:00 p.m.

In Loving Memory

Crystal Ballroom D & E

A tribute to Oley members and friends who have died in the past year.

12:00 p.m. — 2:00 p.m.

Raffle Day in the Exhibit Hall/Lunch

Atrium

Visit exhibits to enter contests. Drawing will be held at 1:30 p.m. Must be present to win. Complimentary lunch served.

2:15 p.m. — 4:30 p.m.

Youth Activity

Crystal Ballroom E

See page 4 for details.

2:15 p.m. — 3:15 p.m. Breakout Session I

3:30 p.m. — 4:30 p.m. Breakout Session II

(choose two)

- *Session I only: Skin/Wound Care/Ostomy Issues*
TBD
Odyssey B
- *Session II only: Navigating Ostomy Issues with New Device*
Michael Seres
Odyssey B
- *Arranging the Best IEPs*
Donna Noble
Atlantis A
- *Wisdom Specific to Pediatric SBS*
Arlet Kurkchubasche, MD, FACS, FAAP
Fantail
- *Transition to Independence: It Takes a Village*
Roy George; Madalyn George Thiemann, RN
Cobia
- *Catheter Related Bloodstream Infections: What Role Does Your Needleless Connector Play?*
Christine Cavanaugh, RN, CRNI
Bluegill
- *Compromised Absorption? Your Diet Matters!*
Laura Matarese PhD, RD, LDN, CNSC, FADA, FASPEN
Hinalea
- *Food Allergies and Sensitivities*
Carol Ireton-Jones, PhD, RDN, LD, CNSC, FASPEN, FAN; Donald George, MD
Coral Ballroom A
- *Medication Delivery in SBS/Intestinal Failure: What Are the Essential Considerations?*
Reid Nishikawa, PharmD, BCNSP, FCSHP; Brenda Gray, PharmD, BCNSP, CNSC
Coral Ballroom B



Parking Discount

Oley guests will enjoy fifty percent discount on parking at the Renaissance.

• *Session I only: Maintaining Relationships with Friends/Family, etc.*

Amanda Singer; Donna Yadrich, MPA, CCRP
Coral Ballroom C

• *Session II only: Maintaining Relationship with Yourself*

Amanda Singer; Donna Yadrich, MPA, CCRP
Coral Ballroom C

• *Diagnosing and Managing Eosinophilic Esophagitis*

Jeffrey A. Bornstein, MD
Mako

• *Future Cures/Options for Intestinal Failure & SBS:*

Growing Intestine, Transplantation and Growth Hormone

Charlene Compher, PhD, RD, FADA, CNSC, LDN; Daniel H. Teitelbaum, MD; Kishore Iyer, MBBS, FRCS, FACS
Crystal Ballroom D

8:00 p.m. — 10:00 p.m.

Jammin' Jammies

Odyssey A & B

See page 4 for details.

Thursday

10:30 a.m. Registration/11:00 a.m. Walk

Walk-a-Thon

Renaissance Atrium

See page 4 for details.

11:30 a.m. — 3:00 p.m.

Picnic

Atrium

See page 4 for details.

Friday

10:00 a.m. — noon

No-Host Farewell Breakfast

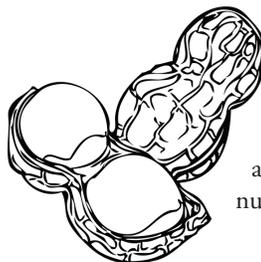
Tradewinds

See page 4 for details.



Thank You Faculty

Thanks to all the faculty who have volunteered to share their expertise in home nutrition support and related issues. The success of the Oley Conference depends heavily on the efforts of these dedicated individuals!



Please Don't Eat/Handle Nuts!

One of the Oley conference attendees has a severe allergy to nuts. Please refrain from handling or eating nuts in public areas and during Oley meetings and events.

Special Sponsorships

Many thanks to the following companies and individuals for their generous contributions.

2014 Oley Awards

Abbott Nutrition; BioScrip; Coram CVS/specialty infusion services; Nutrishare; ThriveRx. Program: New York Press & Graphics.

Ambassador Workshop

NPS Pharma

Breakfast

Tuesday: Walgreens Infusion Services

Commemorative T-shirt

Kimberly-Clark

Conference Badges

BioScrip

Conference Program

Coram CVS/specialty infusion services

Elevator Wrap

Nutrishare, Inc.

Emergency Medical Support

Coram CVS/specialty infusion services

Exhibit Hall Score Card

AMT; Baxter Healthcare; Coram CVS/specialty infusion services; CORPAK MedSystems; Kimberly-Clark; Nestlé; NPS Pharma; Real Food Blends; ThriveRx; Walgreens Infusion Services

First-Time Attendee Orientation

Nutrishare, Inc.

Hotel Room Keys

Coram CVS/specialty infusion services

Jammin' Jammies

Abbott Nutrition

Picnic

Fresenius Kabi USA

Registration Bags

Nutrishare, Inc.

Registration Bag Inserts

BioScrip; Covidien

Rehydration Station

ThriveRx

Silent Auction Massage

Lesley Marino

Speaker Support

11th Health & Technologies; Albany Medical Center; Alpert Medical School of Brown University/Rhode Island Hospital; ASPEN; Arnold Palmer Hospital; Baxter Healthcare; BioScrip Infusion; Boston Children's Hospital; Brody School of Medicine/East Carolina University; Coram CVS/specialty infusion services; Florida Network of the Association for Vascular Access; Mayo Clinic Florida; CS Mott Children's Hospital; Mount Sinai Medical Center; Nutrishare, Inc.; St. Joseph's Children's Hospital/AngioDynamics; ThriveRx; University of Florida College of Medicine/Nemours Children's Clinic; University of Florida Jacksonville; University of Kansas; University of Pennsylvania, School of Nursing

Travel Scholarships for Consumers

NPS Pharma; Esther Ann Brown Adler Memorial Scholarship; Jarol Boan, MD, MPH; Melissa Chaney Memorial Fund; Friends of Robin Lang Memorial Travel Fund; Bruce F. Groeber Family; Carol Ireton-Jones, PhD, RD, LD, CNSC, FASPEN, FAND; Carol & Jack Leibee; Judy Peterson, RN, MA; Janet Platt & Christopher Hlatky; Short Bowel Syndrome Foundation; ThriveRx

Tube Feeding Workshop

Sponsored in part by Nestlé

Videotaping of Conference

NPS Pharma

Walk-a-thon

AMT; Baxter Healthcare; BioScrip; Coram CVS/specialty infusion services; Covidien; Fresenius Kabi USA; ThriveRx; Walgreens Infusion Services; Xeridien

Youth Activity

Wednesday: Walgreens Infusion Services



A special shout out to the following companies who have underwritten events with food:

Fresenius Kabi USA—*Picnic*
NPS Pharma—*Ambassador Workshop*
Walgreens Infusion Services—*Tuesday's Breakfast*

Exhibitors



11 HEALTH & TECHNOLOGIES
Kinetic Business Centre
Borehamwood, Herts WD6 4JP, UK
www.11health.com

11 Health has developed the Ostom-i Alert sensor, an innovative device that alerts patients as to how full their ostomy pouches are so they can decide if and when to empty them. The device captures guidance information about volume of output over a time period, allowing patients to email that information.



3M HEALTH CARE
3M Center, 275-04-W
St. Paul, MN 55144
www.3M.com/Securement

3M Health Care offers solutions in the medical, oral care, drug delivery, food safety, and health information markets. They have an unparalleled ability to connect people, insights, science, and technology to think beyond today, solve problems, and make better health possible.



ABBOTT NUTRITION*
3300 Stelzer Rd
Columbus, OH 43219
www.abbottnutrition.com

Abbott Nutrition is one of the world's leading authorities in science-based nutrition for all stages of life. Its portfolio of products includes Jevity, Vital, PediaSure Peptide, and EleCare, to help patients grow and achieve greater well-being. Visit www.AbbottNutrition.com to find information and education materials to help increase tube-feeding knowledge.



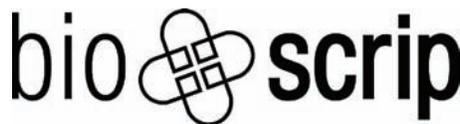
APPLIED MEDICAL TECHNOLOGY, INC (AMT)*
8000 Katherine Blvd
Brecksville, OH 44141
www.appliedmedical.net

Applied Medical Technology, Inc. (AMT) helped develop the PEG tube, and its founder co-invented the first low-profile feeding device. AMT continues to make innovative medical devices, including the AMT Bridle™ Nasal Tube Retaining System, the AMT MiniONE® low-profile buttons, and the new AMT G-JET® low-profile G-J enteral tube.



BAXTER HEALTHCARE*
25212 West Illinois Rte 120, WG1-3S
Round Lake, IL 60073
www.clinimix.com

Baxter Healthcare Corporation has eighty years' experience in developing parenteral nutrition products that work together to help improve patient outcomes. Baxter offers clinicians and patients parenteral nutrition solutions, IV fat emulsions, and automated compounding systems.



BIOSCRIP INFUSION SERVICES*
10050 Crosstown Circle, Ste 300
Eden Prairie, MN 55344
www.bioscrip.com

BioScrip® is a leading national provider of comprehensive, cost-effective pharmaceutical and home care solutions. Their goal is to partner with patients, physicians, health care payors, government agencies, and pharmaceutical manufacturers to provide access to infusible medications and management solutions that optimize outcomes for chronic and other complex health care conditions.

Boston Scientific

Advancing science for life™

BOSTON SCIENTIFIC*
100 Boston Scientific Way
Marlborough, MA 01752
www.bostonscientific.com

Boston Scientific Endoscopy is a world leader in less invasive medical devices for treating gastrointestinal and pulmonary conditions. The company provides customers unmatched value by combining its clinically proven technologies with superior support to help improve patient outcomes and reduce total cost of patient care.



CALMOSEPTINE, INC
16602 Burke Lane
Huntington Beach, CA 92647
www.calmoseptine.com

Calmoseptine® Ointment protects and helps heal skin irritations from moisture, such as urinary and fecal incontinence. It is also effective for irritations from perspiration, wound drainage, fecal and vaginal fistulas, and feeding-tube site leakage. Calmoseptine temporarily relieves discomfort and itching. Free samples at their booth!



CERA PRODUCTS, INC
55 Mathews Dr, Ste 220
Hilton Head Island, SC 29926
www.ceraproductsinc.com

Cera Products' scientifically developed and physician recommended rice-based oral rehydration products include CeraLyte®, a medical rehydration product for preventing and correcting severe dehydration from diarrhea, and CeraSport®, a high performance hydration drink series for sweat replacement. All products are certified gluten-free, providing essential electrolytes, with no added sugars or fruit juices.

Exhibitors



CORAM CVS/SPECIALTY INFUSION SERVICES*

555 17th St, Ste 1500

Denver, CO 80202

www.coramhc.com

Through a national network of over eighty-five locations, Coram CVS/specialty infusion services offers comprehensive home infusion services. They provide home parenteral and enteral services through their Nourish™ Nutrition Support Program. With over thirty years of experience, they are dedicated to providing high-quality clinical care and personal support for nutrition consumers.



CORPAK MEDSYSTEMS

1001 Asbury Dr

Buffalo Grove, IL 60089

www.corpakmedsystems.com

CORPAK MedSystems' enteral feeding tubes and accessories provide clinicians, caregivers, and patients all the options they need for successful enteral feeding. Included are NG/NI feeding tubes, PEGs, G-tubes, LPGDs, and the FARRELL® Valve System to assist those with issues of enteral feeding intolerance. CORPAK also offers Clog Zapper to keep the feeding tube functioning.



COVIDIEN*

15 Hampshire St

Mansfield, MA 02048

www.covidien.com

Covidien is a leading global health care products company that creates innovative medical solutions for better patient outcomes and delivers value through clinical leadership and excellence. Covidien develops, manufactures, and sells a diverse range of industry-leading medical device and supply products. Visit www.covidien.com to learn more about its business.

Dietitians in Nutrition Support

a dietetic practice group of the

eat right. Academy of Nutrition and Dietetics

DIETITIANS IN NUTRITION SUPPORT, ACADEMY OF NUTRITION AND DIETETICS

10 Leah Dr

Cranston, RI 02921

www.dnsdpg.org

DNS is a Dietetic Practice Group in the Academy of Nutrition in Dietetics. DNS focuses on integrating the science and practice of enteral and parenteral nutrition in order to provide appropriate nutrition support therapy to adult and pediatric patients in hospital, at home, and throughout the health care continuum.



feeding matters

FEEDING MATTERS

7650 E Redfield Rd Ste C-4

Scottsdale, AZ 82560

www.feedingmatters.org

Feeding Matters is spearheading the effort to conquer pediatric feeding struggles. Their mission is to bring pediatric feeding struggles to the forefront so infants and children are identified early, families' voices are heard, and medical professionals are equipped to deliver collaborative care.



FUNCTIONAL FORMULARIES

292 Inwood Rd

Wilmington, OH 45177

functionalfomularies.com

Functional Formularies has developed the world's first shelf-stable plant-based organic whole foods feeding-tube formula and oral meal replacement, called Liquid Hope. Liquid Hope is gluten free, dairy free, corn free, soy free, GMO free, and BPA free.



GLOBAL ENTERAL DEVICE SUPPLIER ASSOCIATION (GEDSA)

692 N High St, Ste 207

Columbus, OH 43215

gedsa.org/about.html

GEDSA is a nonprofit trade association formed to introduce international standards for medical device tubing connectors. Comprised of manufacturers, distributors, and suppliers worldwide, GEDSA facilitates information flow about the Stay Connected initiative, designed to increase patient safety, and optimize enteral feeding delivery by reducing the risk of tubing misconnections.



*Trusted Clinical Solutions**

KIMBERLY-CLARK HEALTH CARE*

1400 Holcomb Bridge Rd

Roswell, GA 30076

www.kchealthcare.com/home.aspx

Kimberly-Clark—The Enteral Feeding company—strives to deliver easy and reliable enteral feeding solutions. Kimberly-Clark makes MIC® and MIC-KEY® balloon-retained gastrostomy and transgastric-jejunal feeding tubes. For pediatric and adult patients, these tubes provide safe, reliable nutrition delivery, with more tube options than any other company.

Exhibitors (cont.)



MITOACTION
PO Box 51474
Boston, MA 02205
www.mitoaction.org

MitoAction's mission is to improve the quality of life for everyone affected by mitochondrial disease through support, education, outreach, and advocacy initiatives.



THE NEBRASKA MEDICAL CENTER
988132 Nebraska Medical Center
Omaha, NE 68198
www.nebraskamed.com/transplant

With a reputation for excellence and extraordinary patient care, the Nebraska Medical Center is ranked one of America's Top Hospitals. As the teaching hospital for the University of Nebraska Medical Center, this 627 licensed bed academic medical center has an international reputation for solid organ and bone marrow transplantation.



NESTLÉ HEALTHCARE NUTRITION*
12 Vreeland Rd
Florham Park, NJ 07932
www.nestlehealthscience.com

Nestlé Health Science strives to make a positive difference to the nutritional health, well-being, and quality of life of patients through the development and delivery of innovative, medically recognized branded nutritional solutions for acute and chronic conditions.



NPS PHARMA*
550 Hills Dr, 3rd Fl
Bedminster, NJ 07921
www.npsp.com

NPS Pharma is a global biopharmaceutical company working to change the lives of patients with rare diseases. Their Short Bowel Syndrome franchise is led by approved treatments for adults in the US and EU, and complemented by a clinical program for pediatric patients. For more information about NPS Pharma, visit NPSP.com.



NUTRISHARE, INC*
9850 Kent St
Elk Grove, CA 95624
www.nutrishare.com

Nutrishare, your home TPN specialty company since 1991, is proud to announce their expansion into Canada. Be sure to visit the Nutrishare Canada booth! And check out the elevators for the "Wheel of Fortune" rules to win free prizes at the Nutrishare Canada booth.



NUTRISHARE CANADA*
2180 Steeles Ave W
Unit 4, Concord, ON, L4KZ5
www.nutrishare.ca

Rod Okamoto and Tom Diamantidis founded Nutrishare twenty-three years ago, focusing exclusively on the home TPN consumer. Nutrishare Canada is dedicated to the same standard of excellence and commitment to their Canadian home TPN consumers.



PATCHWORK PEDDLER
PO Box 290
Crossville, TN 38557
www.PatchworkPeddler.com

Your place to get premium handmade feeding tube accessories. The company says its "bamboo pads aid in reducing granulation tissue with antibacterial, hypoallergenic, antimicrobial, and antifungal properties—saving you stress and money." Serving you and donating to the community since 2009. Save 10% on orders using "OLEY Conference" code.



REAL FOOD BLENDS
PO Box 2126
Chesterton, IN 46304
www.realfoodblends.com

Real Food Blends makes shelf-stable, 100% real food meals for people on feeding tubes. Their meals can add nutritional variety into a tube-fed person's diet or supplement a homemade blended diet.



SBS CURE PROJECT
18654 Kalmar Path
Lakeville, MN 55044
www.SBSCure.org

SBS Cure Project is dedicated to finding a "cure" for short bowel syndrome (SBS). SBS Cure is determined to educate SBS brothers and sisters about their treatment options and to do everything possible to find a cure.

** Indicates a company is also a corporate donor*

Exhibitors (cont.)



SBS FOUNDATION
4830 Wilshire Blvd
Lincoln, NE 68504

The Short Bowel Syndrome Foundation's mission is to educate, support, and empower patients who live with the condition and the health care providers who help patients to manage SBS. SBSF empowers patients and their families to live fuller lives by connecting them to necessary resources, creating a lifeline of hope.



THRIVERx*
10828 Kenwood Rd
Cincinnati, OH 45242
www.thriverx.net

A proud Oley Gold Medallion Partner, ThriveRx is dedicated to providing customized customer service and clinical care for the home enteral and parenteral nutrition consumer. Its mission is to ensure quality care that fosters independence and empowers patients and their families. Visit their exhibit and learn more about their Short Bowel Program.

Trendy Tubies

The one stop shop
for all things tubie

www.trendytubies.com

TRENDY TUBIES
PO Box 9362
Chesapeake, VA 23321
www.trendytubies.com

Trendy Tubies is "the one stop shop for all things tubie." Trendy Tubies makes tube feeding fun. The company offers modified backpacks for feeding pumps, insulated and non-insulated feeding bag covers, syringe rolls, pole buddies, and the JA-10G G-tube protective belt.

Walgreens Infusion Services

WALGREENS INFUSION SERVICES*
200 Wilmot Rd
Deerfield, IL 60015
www.healthcare.walgreens.com/healthcare/healthcare-professionals.jsp

Walgreens Infusion Services supports the needs of home enteral and parenteral nutrition patients of all ages and conditions. Multidisciplinary teams provide individualized care and comprehensive services designed to achieve optimal health outcomes. Care coordination facilitates a smooth transition from hospital to home. All Walgreens infusion locations are ACHC accredited.



XERIDIEM
4700 S Overland Dr
Tucson, AZ 85714
www.xeridiem.com

Xeridiem is a vertically integrated silicone expert in single-use medical devices with a reputation for working transparently with customers to provide excellent service and superior quality. The design, development, and manufacturing emphasis are on improving enteral feeding devices for improved patient comfort and performance. FDA Registered, ISO 13485:2012.



Planning for Your Flight Home

Navigating airport security can be challenging, especially with implanted devices, medical foods, intravenous bags, pumps, ostomies and various medications, etc. We want to remind Oley conference attendees to take advantage of the Transportation Security Administration program, TSA Cares.

It is recommended that you call (855) 787-2227 approximately 72 hours ahead of travel so that TSA Cares has the opportunity to coordinate checkpoint support with a TSA Customer Service Manager located at the airport when necessary. Notifying them of your medical issues, items you are traveling with, times, airline, etc. allows them the opportunity to organize staff accordingly.

To learn more about TSA Cares visit:

www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions

Safe travels!

Conference Faculty

PENNY L. ALLEN, RD, LD, CNSC
Nutrition Support Consultant
Bedford, NH

Penny is a Registered Dietitian and Certified Nutrition Support Clinician (CNSC). She has over twenty-five years of nutrition support experience, primarily in the home infusion/home parenteral nutrition (HPN) arena. In her career, she has served in many different roles: clinical and patient care, HPN-related program development (regional and national), and sales and marketing.

Penny earned a BS in Nutrition and Dietetics from the University of New Hampshire and completed a post-grad internship at Beth Israel Hospital in Boston, Massachusetts. Penny currently serves on the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) Public Policy Committee.

Penny was responsible for the growth and development of Critical Care Systems' specialty nutrition support program. Most recently, she served as their National Director, Nutrition Support, where she provided clinical, sales, and marketing field support for this former infusion provider. She serves as a subject matter expert for Medicare qualification issues related to PN, provides nutrition support (PN) continuing education presentations to payors, physicians, hospitals and clinicians, and continues to provide assessment and clinical monitoring for HPN patients. Penny co-authored the 2012 A.S.P.E.N. Position Paper, "Clinical Role for Alternative Intravenous Fat Emulsions," and has also authored/co-authored numerous nutrition support practice abstracts presented at Clinical Nutrition Week over the last decade.

KATHRYN BUNDY
SBS Cure Project/ Nutrishare, Inc.
Los Angeles, CA

Kathryn is in her thirtieth year of home parenteral nutrition (HPN), having developed Crohn's Disease at age seven (1970), and having been left with less than 20 percent of her intestines after a radical resection in 1985 due to extensive disease and no medical treatment. From the first week of HPN, Kathryn has

thrived and pursued her acting career, as well as a lengthy stint in live graphic design for TV shows and sports events, and post-production for film and TV graphic design.

Kathryn got her start as a professional actor and standup comic in New York City, and then moved to Los Angeles to pursue a film and TV career. You may have seen her in many national commercials (Pizza Hut, McDonald's, 1-800-DENTIST...), television shows (*Men of a Certain Age*, *CSI*, *New York Love Stories*...), and feature films (*Relax, The Ones*...). After a ten-year hiatus focused on medical issues, Kathryn will be rejoining her career in early 2015.

Having spent almost her entire life with Crohn's and short bowel syndrome, Kathryn has joined forces with other patients to create the SBS Cure Project, which raises money for research to find a cure(s) for SBS. She has also been on Gattex for four and a half years, and looks forward to sharing her experience.

Kathryn has been on Gattex for four and a half years now; she was in three studies and has purchased the drug since it became available on the market in March 2013. (She notes, "When I say purchase, I mean my copay is \$0! I have Medicare Part D which pays the bulk of the drug and charitable donations from Patient Access Network which pays the copays.")

Kathryn has been on home parenteral nutrition (HPN) since July 26, 1985—2 liters of PN and 2+ liters of hydration every night and day, for 28+ liters of infusions per week. Since starting on the labeled drug in the extension study January 12, 2010, she has been able to decrease her infusions down to 4 liters of PN and 1 liter of hydration per week. She is hoping to transition off of HPN this year, if all goes well. She has gone from seven nights of infusing down to two and a half.

CHRIS CAVANAUGH, RN, BSN, CRNI,
VA-BC, CDTC
Clinical Education Manager
RyMed Technologies, LLC
3606 Molona Drive
Orlando, FL 32837-5830

Chris is a nationally-certified, registered nurse who specializes in vascular access and infusion therapy. She has experience in medical industry support and education, acute care, long term care and home health care. She has presented at local, regional and national meetings, and has published in national healthcare newsletters and the Journal of Radiology Nursing.

KATELYN CHOPY, MS, RD, LDN
Pediatric Clinical Dietitian
Rhode Island Hospital/ Hasbro Children's Hospital
593 Eddy St
Providence, RI 02903

Katelyn completed her master's degree and dietetic internship at the University of Rhode Island. Her thesis research was focused on the value of the Oley Foundation for home parenteral and enteral nutrition (HPEN) consumers. She is a Registered Dietitian with a focus in pediatrics. As a recipient of the 2014 HomePN Research Prize, Katelyn will present information from her manuscript entitled, "A Qualitative Study of the Perceived Value of Membership in the Oley Foundation by Home Parenteral and Enteral Nutrition Consumers."

CHARLENE COMPHER, PHD, RD,
FADA, CNSC, LDN
Professor of Nutrition Science
University of Pennsylvania, School of Nursing
418 Curie Blvd
Philadelphia, PA 19104-4217

Dr. Compher is Professor of Nutrition Science at the University of Pennsylvania, School of Nursing. She is the dietitian member of a multi-disciplinary home parenteral nutrition (HPN) team at the Hospital of the University of Pennsylvania in Philadelphia, Pennsylvania. As Editor of the American Society for Enteral and Parenteral Nutrition's clinical guidelines, she has led efforts to improve the care of nutrition support patients by publishing fifteen clinical guidelines since 2009. One of the recent guidelines addresses strategies to prevent liver disease in pediatric HPN patients. She was the local investigator for studies on the drug Gattex.

MARK DELEGGE, MD
Senior Global Medical Director, Baxter Healthcare
Medical Director, Coram CVS/specialty infusion services
Medical Director, DeLegge Medical
2356 Darts Cove Way
Mt. Pleasant, SC 29466

Dr. DeLegge is a long-time member of the Oley Foundation and the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). He is the Medical Director at DeLegge Medical, which focuses on research and design.

Names and addresses are provided for educational purposes only. The Oley Foundation requests that in the true spirit of the Oley mission, this listing not be used for the purpose of sales.

Faculty (cont.)

**MARIANNE DUDA, MS, RDN, LD/N,
CNSC**

**Clinical Nutritionist
ThriveRx**

**10828 Kenwood Rd
Cincinnati, OH 45242**

Marianne has over fifteen years of experience successfully managing all aspects of the provision of home parenteral and enteral nutrition (HPEN) therapies. Her experience also includes the successful development, implementation, and management of home nutrition support programs for home infusion providers. Earlier in her career, she provided clinical nutrition services to individuals across the continuum of care, and she has an extensive background in nutrition support in the acute care setting.

Marianne is the 2013 recipient of the Distinguished Nutrition Support Dietitian Service Award from the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and Chair of A.S.P.E.N.'s Dietetics Practice Section. She has served on the Nutrition Support Certification Examination Committee and the A.S.P.E.N. Online Self-Assessment Program Committee, and has co-authored many home nutrition support-related abstracts and posters.

A past-president of the Florida Society for Parenteral and Enteral Nutrition, Marianne also co-chaired the 2009 Oley Foundation Conference, was a 2009 Nominee for the Oley Foundation's Award for the Ultimate Volunteer, and a 2007 nominee for the Dietitians in Nutrition Support Outstanding Service Award.

DONALD GEORGE, MD

**Clinical Associate Professor of Pediatric
Gastroenterology and Nutrition, University
of Florida College of Medicine
Chief, Division of Gastroenterology and
Nutrition**

**Nemours Children's Clinic
807 Children's Way
Jacksonville, FL 32207**

Dr. George's distinguished career began at Johns Hopkins University in Baltimore, Maryland. He obtained his medical degree from SUNY at Buffalo School of Medicine and completed his pediatric and post-doctoral training in Pediatric Gastroenterology at Children's Hospital of Buffalo.

Dr. George left New York to take a position as Assistant Professor of Pediatric Gastroenterology with the University of Florida College of

Medicine. After four years, he went on to lead the Pediatric GI and Nutrition Division at the University of Texas Health Science Center. He returned to Florida, and is currently a Clinical Associate Professor of Pediatric Gastroenterology and Nutrition at the University of Florida College of Medicine and Chief, Division of Gastroenterology and Nutrition at Nemours Children's Clinic.

Dr. George has participated in many professional organizations, such as the Childhood Obesity Prevention Coalition; the Florida Society of Parenteral and Enteral Nutrition; the AAP; and A.S.P.E.N. He serves as author and editor for A.S.P.E.N.'s pediatric core curriculum and Guidelines for Pediatric Intestinal Rehabilitation, and helped author the AAP guidelines for home enteral and parenteral nutrition (HPEN). His contributions in pediatric nutrition include a dozen book chapters and over forty papers. However, he says, "I am perhaps most proud of the fact that I have been invited to participate in Oley Foundation events for over twenty-five years."

ROY GEORGE

**MADALYN GEORGE THIEMANN, RN
HPN Consumer and Parent
Oley Ambassador
Chesapeake, VA**

Roy says he is thrilled to be a presenter at this year's conference. Roy has been a nutrition support consumer since birth and grew up with the Oley Foundation. He's excited, along with his mother Madalyn, to give back, and has recently signed on to be an Oley Ambassador. Roy has been blessed to have performed in various venues as a pianist, singer, or actor. He currently resides with his family in Chesapeake, Virginia, where he's finishing school and getting certified as an American Sign Language interpreter. This presentation is lovingly dedicated to Alisha Hoelle and the Hoelle family.

BRANDI GERHARDT, RN, BAN

**Clinical Nurse Coordinator, Intestinal
Rehabilitation
The University of Nebraska Medical Center
983285 Nebraska Medical Center
Omaha, NE 68198-3285**

Brandi started at the University of Nebraska Medical Center in 1998, soon after graduating from nursing school. She worked in the pediatric intensive care unit, which primarily serviced

liver/intestinal transplant patients and traumas. In 2000, she decided to work in an adult critical care unit for some additional experience, but she went back to UNMC when a job as a pediatric nurse coordinator with the liver/intestinal transplant team opened up in 2001. At the time she was hired, the Intestinal Rehabilitation Program (IRP) was just starting and she took on a dual role as a transplant coordinator and helping with the IRP team. In 2003, she became the nurse coordinator for the IRP team and has been there ever since.

After sixteen years in intestinal rehabilitation and transplant, she says she does not want to move on to anything else: "I have a strong passion for what I do. I have the fortunate luck to be a part of such a unique medical team and amazing patient population. Intestinal Failure requires a lifelong commitment to a complicated medical condition—our team chooses to focus our program like a family as we will be with many of our patients for their lifespan. We are very lucky to be a part of their lives!"

BETH GORE, PHD, MBA

**Advocate, Speaker, Author
Brandon, FL**

Beth is a mother to six children, all adopted with special needs. Manny, her youngest, became tube fed at age eight months and became parenteral nutrition (PN) dependent at age two. He's now almost five. Manny has spent over one-third of his life in the hospital. Through sepsis, line breaks, and drug overdoses, Beth has learned how to advocate for her son and for other patients. As a result, she is now on the Board of Directors for the AVA Foundation. She is currently writing a book about surviving the hospital from a caretaker point of view. As a keynote speaker, she speaks for those who cannot speak for themselves.

Beth has a BA in Psychology, BA in Theology, MA in Educational Psychology, and PhD in Training and Development, with an MBA minor and a minor in statistics.

Faculty (cont.)

**BRENDA GRAY, PHARMD, BCNSP,
CNSC**

**National Director of Pharmacy
BioScrip Infusion
Tampa, FL**

In addition to serving as National Director of Clinical Pharmacy for BioScrip Infusion, Dr. Gray provides consulting services in the areas of home infusion, nutrition, and pediatrics to several universities. Her role includes direct patient care, as well as the development of multi-disciplinary policy and procedures and continuing education programs related to clinical practice, stability, and pharmacy practice. Dr. Gray has practiced home infusion pharmacy since 2000. Prior to that she had extensive experience in managed care including a variety of practice settings and models. Dr. Gray has dual certification in nutrition support from the Board of Pharmacy Specialists and the National Board of Nutrition Support Certification (NBNSC), completed an ASHP accredited pediatric pharmacy residency and taught pharmacy, nursing and medical students. Dr. Gray currently serves on leadership committees for several national organizations including the Board of Directors for NBNSC and has worked internationally in health care. She has presented multiple posters, published several patient directed articles and contributed to texts including recently as a writer for *Extended Stability for Parenteral Drugs*, 5th Edition.

After years of supporting the nutrition support consumer community, she experienced her own health crisis and became a home parenteral nutrition consumer in March 2013. Since this time, she has published an article outlining her experience and shared this with national organizations as well as serving in a patient advocacy role for BioScrip.

PEGGI GUENTER, PHD, RN

**Senior Director of Clinical Practice, Quality,
and Advocacy**

**American Society for Parenteral and Enteral
Nutrition**

**8630 Fenton St, Ste 412
Silver Spring, MD 20910**

In her position as Senior Director of Clinical Practice, Quality, and Advocacy for the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), Dr. Guenter oversees the development of standards, guidelines, and safe practices for nutrition support, and advocacy

efforts for professionals and patients. She served as lead author for the Joint Commission Journal on Quality and Patient Safety position paper on enteral misconnections published in 2008. Dr. Guenter is well known in the field of nutrition support as a clinical nurse specialist, researcher, and author of over one hundred peer-reviewed abstracts, journal articles, book chapters, and books. She was previously Editor-in-Chief of *Nutrition in Clinical Practice*.

**KATHLEEN M. GURA, PHARMD,
BCNSP, FASHP, FPPAG**

**Clinical Pharmacist GI/Nutrition
Team Leader, Surgical Programs
Boston Children's Hospital
300 Longwood Ave
Boston, MA 02115**

Dr. Gura is the Team Leader with the Surgical Program and a clinical pharmacist with the Clinical Nutrition Service in the Division of Gastroenterology and Nutrition at Boston Children's Hospital. She is also an Associate Professor of Pharmacy Practice at the Massachusetts College of Pharmacy in Boston. Certified as a Nutritional Support Pharmacist, Dr. Gura is a Fellow of the American Society of Health-System Pharmacists and the Pediatric Pharmacy Advocacy Group (PPAG). She is also a member of several pharmaceutical societies, including the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and the European Society for Parenteral and Enteral Nutrition (ESPEN). She has received numerous awards, including the 2012 Distinguished Pharmacist Award from A.S.P.E.N. and the 2008 ASPEN Serlick Award for safe practice in the field of parenteral nutrition (PN).

Dr. Gura has written several book chapters on pediatric nutrition and many articles for peer-reviewed journals on topics such as PN-associated cholestasis, clinical practice guidelines for PN, and the use of PN in the neonate.

TOM HANCOCK

Tom Hancock

Executive Director

**Global Enteral Device Supplier Association
(GEDSA)**

**692 N High St, Ste 207
Columbus, OH 43215**

As Executive Director for the Global Enteral Device Supplier Association (GEDSA), Tom is currently leading the coordinated effort to

introduce new enteral tube feeding connectors through an initiative known as Stay Connected. GEDSA is working in collaboration with the Joint Commission, Association for the Advancement of Medical Instrumentation (AAMI), FDA, and a host of partner associations, including the Oley Foundation, representing various health care professionals, practice experts, advocacy groups, and manufacturers/suppliers. The mission of the initiative is to represent a unified voice in the seamless introduction of new International Standards for small-bore connectors to reduce the risk of tubing misconnections and improve patient safety. Tom has more than fifteen years in health care as a marketer, business leader, and consultant. Most recently Tom held director-level positions in marketing at Abbott, managing their pediatric nutrition, specialty nutrition, and medical device businesses. Tom has also served in various leadership roles at Saatchi & Saatchi Healthcare Advertising and Bristol-Myers Squibb.

LYN HOWARD, MB, FRCP

**Professor Emeritus, Albany Medical College
Former Head of Clinical Nutrition Program,
Albany Medical Center (1972–2008)
Medical Director and Co-founder, The Oley
Foundation**

43 New Scotland Ave

Albany Medical Center, MC 28

Albany, NY 12208

In the early 1970s Dr. Howard sent her first patient home on nutritional support, and since then she has been published widely in the home parenteral and enteral (HPEN) arena. With Clarence ("Oley") Oldenburg's family support, Dr. Howard started the Oley Foundation in 1983. She is an advocate of the consumer voice in the organization and implementation of HPEN. She is now retired, but she continues research pertinent to HPEN. She is currently working on a national committee to update parenteral micronutrients. She lives on a farm and is an avid horse driver.

**CAROL IRETON-JONES, PHD, RD, LD,
CNSC, FASPEN, FAND**

**Consultant Director, Nourish COE Coram
CVS/specialty infusion services**

Dietitian in Private Practice

170 Countryside Dr

Carrollton, TX 75007

Dr. Ireton-Jones has many years of experience

Faculty (cont.)

in nutrition support and has been coming to the Oley Foundation conferences since 1996, sharing and receiving knowledge with and from home parenteral and enteral nutrition (HPEN) consumers.

KISHORE IYER, MBBS, FRCS, FACS
Associate Professor of Surgery and Pediatrics
Recanati/Miller
Transplantation Institute Director, Adult & Pediatric Intestinal
Transplantation and Rehabilitation Program
Mount Sinai Medical Center
1 Gustave L Levy Place, Box 1104
New York, NY 10029

Dr. Iyer is the director of adult and pediatric intestinal transplantation and rehabilitation at Mount Sinai Medical Center in New York, surgical director of pediatric liver transplantation, and an associate professor of surgery and pediatrics at the Mount Sinai School of Medicine.

Dr. Iyer trained in general surgery and pediatric surgery in the UK, where he worked with Dr Adrian Bianchi and developed his early interest in short bowel syndrome and the use of intestinal lengthening procedures. He pursued research at the Great Ormond Street Hospital for Sick Children in London, winning the 1996 British Association of Pediatric Surgeons Prize for his pioneering work identifying phytosterols in soy-based lipid emulsions as a potential cause for parenteral nutrition-associated liver disease in patients with intestinal failure.

He trained in transplant surgery at Chicago and Omaha. He was responsible for establishing the intestinal rehabilitation program in Omaha, which he directed before moving to Chicago to establish a similar program at Northwestern University/Children's Memorial Hospital. His clinical and research interests are in the areas of intestinal failure, intestinal transplant, and PN-associated liver disease, as well as mathematical modeling for complex clinical decision-making. He has published extensively in these areas.

Dr. Iyer is a Fellow of the Royal College of Surgeons of England and a Fellow of the American College of Surgeons. He has served on several national and international professional committees and on the Oley Foundation board of trustees.

PAULA JOHNS, RN, MSN
Nutrition Support Nurse Clinician
UF Health Shands Hospital at the University of Florida
1600 SW Archer Rd
Gainesville, FL 32610

Paula has been a nurse for over thirty-three years. She has worked in the area of nutrition support for the last twenty-five of those years. Her passion, she notes, is for the parenteral nutrition consumers, and educating them and their families on PN—but she has a special passion for home parenteral nutrition (HPN) consumers. Paula is the co-founder of the PICC team at Shands Hospital, with special interest in the prevention of central line infections and quality of life for the HPN consumer.

DARLENE KELLY, MD, PHD
Science and Medicine Advisor
The Oley Foundation
43 New Scotland Ave
Albany Medical Center, MC 28
Albany, NY 12208

Dr. Kelly's interest in home parenteral nutrition goes back to her college days, while her interest in nutrition goes back further—to seventh grade, when she says she was intrigued by the “Basic Seven Food Groups.” Like the basic food groups, her career has taken a variety of turns. She explored her interest in nutrition first as a college student, then as a dietitian, a college nutrition instructor, and a graduate student (both masters and doctoral degrees). She then pursued it as a medical student, resident, and fellow, and finally as a practicing gastroenterologist. Dr. Kelly was the Medical Director of Mayo Clinic Rochester's HPN program for twenty-two years. She served on the Oley Board of Trustees for over ten years, and now serves as Oley's Science and Medicine Advisor. She is also active with the European Society for Nutrition and Metabolism (ESPEN) and their Home Artificial Nutrition (HAN) Work Group. Dr. Kelly has been a valuable contributor at Oley meetings over fifteen years.

MARIA KARIMBAKAS, RD, CNSC
Clinical Nutritionist
ThriveRx
10828 Kenwood Road
Cincinnati, OH 45242

Maria is a registered dietitian and is board certified in nutrition support. She received

her B.S. from the University of Vermont and completed her dietetic internship at Brigham and Women's Hospital, Boston, Massachusetts. Before joining ThriveRx, Maria worked for six years as a clinical dietitian at the Nutritional Restart Center in Hopkinton, Massachusetts, the first intestinal rehabilitation program for consumers with short bowel syndrome (SBS). While at the NRC, Maria co-authored several abstracts, papers, and book chapters on the subject of diet and SBS; she is also the co-author of ThriveRx's Maximize Health Short Bowel Rehabilitation at Home program.

BARBARA AND LEE KLINGLER
Oley Ambassador
Valkaria, FL

Barbara, an Oley Ambassador, has been on home parenteral nutrition (HPN) since 1986 (twenty-eight years) due to a mesenteric infarction that left her with 10 1/2” of small bowel. She went to a nutritional rehabilitation center in 1995, where she was educated on what things to eat. She gets one “mental health night” off of HPN per week, doing only hydration. She has been scuba diving throughout the Caribbean islands and now summers in Alaska, enjoying salmon fishing on the Kenai River while infusing her HPN in the early morning hours. “I believe you can do whatever you put your mind to do, even on HPN. If I get tired, I schedule a nap!”

Lee Klingler is the number one support group of twenty-eight-year HPN veteran, Barbara. Lee has helped her when she had a temporary ostomy and knows how to hang her HPN, but allows her to do it. After hearing from her former ostomy nurse that HPN was her burden, not his, he quit “setting her up” and made her independent. Together they have traveled cross-country on HPN, receiving shipments at a local post office in Yellowstone, the UPS Store in Alaska, and various other stops. “We don't allow HPN to hinder our plans. I am very understanding if Barbara has a bad day and just needs a long afternoon nap. I'll also jump in with household chores, including cooking and cleaning, when she cannot.”

Faculty (cont.)

**ARLET KURKCHUBASCHE, MD, FACS,
FAAP**

**Hasbro Children's Hospital
2 Dudley St, Ste 190
Providence, RI 02905**

Dr. Kurkchubasche is a board certified General and Pediatric Surgeon who practices at Hasbro Children's Hospital in Providence, Rhode Island, where she has been faculty at the Alpert School of Medicine of Brown University since 1997. She received her medical degree from the University of California, Irvine. She then completed her general surgery residency in Portland, Oregon, a research fellowship at the Children's Hospital of Pittsburgh, and a clinical fellowship in Pediatric Surgery at Cardinal Glennon Children's Hospital in St. Louis.

Her interest in intestinal failure developed as a consequence of her involvement with short bowel syndrome patients in Pittsburgh. She was actively involved in clinical and basic science research that related to the developing intestine in the neonate and its host defense, particularly in the setting of necrotizing enterocolitis, the major etiology of intestinal failure in the newborn. This was the foundation for later work on intestinal adaptation, bloodstream infections and cholestasis, which was enhanced by collaboration with her mentors from St. Louis. Further basic science work on liver injury and liver repair mechanisms continued at Brown University with Dr. Thomas Tracy. Clinically, her focus has remained on intestinal rehabilitation, looking for optimal ways of incorporating both medical and surgical interventions, to achieve successful adaptation. She is also the program director for the fellowship in Pediatric Surgery at Brown and has championed the need for pediatric surgeons to remain educated and integrally involved in the nutrition care of their patients.

**LAURA MATARESE, PHD, RDN, LDN,
CNSC, FADA, FASPEN**
Oley Foundation Trustee
**Associate Professor, Department of Internal
Medicine**
**Division of Gastroenterology, Hepatology
and Nutrition**
Brody School of Medicine
East Carolina University
Vidant MA 342, Mail Stop 734
600 Moyer Blvd
Greenville, NC 27834

Dr. Matarese has over thirty years of experience

in nutrition support, education, and program development. She is a long-time supporter of the Oley Foundation and a member of the board of trustees. Her primary interests are intestinal failure, intestinal rehabilitation, and intestinal transplantation. Dr. Matarese has lectured and written extensively on home parenteral nutrition (HPN) issues (including several articles for the LifelineLetter). She is devoted to improving the quality of life for patients with intestinal failure as well as making HPEN safe and effective.

ANN MICHALEK, MD
Oley Foundation Trustee
Albany Medical Center Bariatrics
25 Hackett Blvd, Ste 2
Albany, NY 12208

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 patients when Dr. Howard retired in 2007.

**REID NISHIKAWA, PHARMD, BCNSP,
FCSHP**
Coordinator, Clinical Services
Director of Research
Nutrishare, Inc
9850 Kent St
Elk Grove, CA 95624

Dr. Nishikawa has been involved with nutrition support for over thirty years. He is actively involved with the Oley Foundation, the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), the European Society for Clinical Nutrition and Metabolism (ESPEN), the American Society of Health-Systems Pharmacists (ASHP), and the American Gastroenterological Association (AGA). He has been involved in clinical research that has been presented at local, state, national, and international meetings. His clinical interests include intestinal failure, gastroenterology, and nutrition support. His interests also have focused on reducing complications and improving quality of life for the long-term home parenteral nutrition consumer.

DONNA NOBLE

Donna has a BA in Special Education and M ED in Educational Leadership. She has been a special education teacher for twenty-two years. She is also the parent of four children, each of

whom has an Individualized Education Plan (I.E.P) and special education needs. Donna helped create Individualized Health Plans for children with feeding tubes, ostomies, central lines, and trach/vents.

MARIANNE OPILLA, RN, BSN, CNSC
Nutrishare, Inc
9850 Kent St
Elk Grove, CA

Marianne has been a certified nutrition support nurse for over twenty-five years, specializing in management of safe and effective IV nutrition in the hospital and home settings. She has been with Nutrishare, Inc., since 2005. She has a special interest in researching strategies to reduce and prevent central venous catheter infections in the home parenteral nutrition (HPN) population.

MICHELLE PARK, BA
Medical Student
Stanford University
750 Welch Rd, Ste 116
Palo Alto, CA 94304

Michelle is interested in central venous catheter care and coordination of care for parenteral nutrition (PN) patients, especially pediatric patients and their families. As a recipient of the 2014 HomePN Research Prize, Michelle will present research pertaining to a "Central Line Care Card," a cognitive aid for home PN patients. A pilot study suggests this extremely low-cost intervention may improve management of potential CABSIs while improving patient/family satisfaction. The Central Line Care Card can be downloaded in editable format tinyurl.com/carecard.

CRAIG PETERSEN, RD, CNSD
Nutrishare, Inc

Craig has been involved in the provision of home parenteral and enteral nutrition (HPEN) for the last 34 years. He is actively involved in research involving HPEN, with the goal of identifying practices to reduce complications, provide more efficacious care, and improve quality of life of the HPEN consumer. One of Craig's major areas of interest is the identification and treatment of D-lactic acidosis, a neurological disorder that can occur in short bowel syndrome.

Faculty (cont.)

DEBORAH PFISTER, MS, RD, CNSC
Director of Nutrition
ThriveRx
10828 Kenwood Rd
Cincinnati, OH 45242

As Director of Nutrition, Deb is responsible for overseeing ThriveRx's business initiatives and development of the clinical and advocacy programs. Deb's areas of expertise are within home nutrition support, short bowel patient management, and home parenteral and enteral nutrition (HPEN) reimbursement. She has worked in the home infusion industry since 1990 and also worked at the Nutritional Restart Center.

STEPHANIE PITTS, MSN, RN, CPN,
VA-BC
Clinical Specialist, AngioDynamics
Pediatric Vascular Access Nurse
St. Joseph's Children's Hospital of Tampa
3001 W Dr Martin Luther King Jr Blvd
Tampa, FL 33607

Stephanie Pitts is the current president of the Pediatric Special Interest Group of the Association for Vascular Access. She has been a pediatric nurse at St. Joseph Children's Hospital of Tampa for the past sixteen years and started their pediatric vascular access program. Stephanie recently transitioned to a clinical specialist position with AngioDynamics. She speaks across the country on various topics related to vascular access and is passionate about advancing the science of pediatric vascular access to improve outcomes for our smaller patients.

MICHELLE M. ROMANO, RD, LD/N,
CNSC
Assistant Professor of Nutrition
Mayo Clinic Florida
4500 San Pablo Rd
Jacksonville, FL 32224

Michelle is a Nutrition Support Specialist and former Home Enteral Nutrition Program Coordinator at Mayo Clinic in Jacksonville, Florida, since 1997. She earned a BS in Clinical Dietetics and Nutrition from the University of Pittsburgh. She has been a Certified Nutrition Support Clinician (CNSC) since 1992 and an Assistant Professor of Nutrition with the Mayo Clinic College of Medicine.

Michelle has authored or co-authored several research articles and textbook chapters; has been invited to lecture nationally and internationally

in the areas of enteral nutrition and home enteral nutrition, nutrition support in pancreatitis, liver disease, and bone marrow transplant; and served as Chair of the Dietetic Practice Section of the American Society of Parenteral and Enteral Nutrition (A.S.P.E.N.) from 2010–2012. She is active with the Florida chapter of A.S.P.E.N., serving as President in 2005–2006, and on the yearly Symposium Planning Committee. She serves as preceptor in the Mayo Clinic Florida Dietetics Internship Program and the Mayo Graduate School of Medicine Residency Program.

In 2006 she received the Preceptor of the Year Award from the Mayo Clinic Florida Dietetics Internship program and was nominated for the Distinguished Service Award from the Dietitians in Nutrition Support practice group of the American Dietetics Association.

JAMES S SCOLAPIO, MD
Professor of Medicine
Chief, Division of Gastroenterology
University of Florida Jacksonville
655 West 8th St
Jacksonville, FL 32209

Dr. Scolapio is originally from Clarksburg, West Virginia. He completed his undergraduate education at West Virginia University, and medical school at Marshall University School of Medicine. He completed his residency in Internal Medicine and Gastroenterology Fellowship at the Mayo Clinic, Rochester, Minnesota. Dr. Scolapio is currently Professor of Medicine and Chief of the Division of Gastroenterology at the University of Florida Jacksonville campus. He is also Associate Chairman of Internal Medicine and Program Director of the Gastroenterology Fellowship program.

Dr. Scolapio has over fifteen years of clinical nutrition experience and has published over one hundred articles and book chapters related to nutrition. He has been a mentor to over fifteen dietitians, pharmacists, and physicians in the field of nutrition. Dr. Scolapio is Past President of the Florida Society of Nutrition and Florida Society of Gastroenterology and has served on multiple editorial boards, including the Journal of Parenteral and Enteral Nutrition and Nutrition in Clinical Practice. He has served on local, state, and national nutrition committees, including the American Society of Parenteral and Enteral Nutrition (A.S.P.E.N.); has chaired multiple CME courses, including state and national nutrition

courses; and is a past Associate Dean of CME at the Mayo Clinic. Dr. Scolapio was recognized in 2011 as one of the best Gastroenterologists in the United States and more recently as a top Gastroenterologist in Jacksonville, Florida.

MICHAEL SERES
11 Health & Technologies
Kinetic Business Centre
Borehamwood Herts, England WD6 4JP

Michael was diagnosed at age twelve with the incurable bowel condition Crohn's Disease. In late 2011 he became the eleventh person in Britain to undergo a small bowel transplant, which was performed at the Churchill Hospital in Oxford.

Michael started blogging about his journey through bowel transplant. His blog has over 95,000 followers and he uses social media to develop global online peer-to-peer communities covering over 25,000 patients. He devises social media strategies around patient engagement. Michael mentors patients and their families, and is a published author and professional speaker. He is the patient lead for the main UK health-service tweetchat #NHSSM, a facilitator for Centre for Patient Leadership, and digital strategy advisor to The Patients Association and Oxford Transplant Foundation.

AMANDA SINGER
HPEN Consumer
Plymouth, MA

Amanda Singer is a twenty-five year old dancer from Plymouth, Massachusetts. She first became involved with Oley in 2012, when she found the organization through the Web site Inspire.com. This is her third conference; last year she served as a conference Co-Chairperson, as the conference was close to her home.

Amanda suffers from gastroparesis and has used multiple enteral and parenteral devices, including PICC lines, NG-tubes, GJ-tubes, and G-tubes. Since Amanda's diagnosis in 2011, she has gained knowledge, friendships, and a new perspective on life. She has learned to manage her illness, to the point where she can often eat a variety of foods again and have enough energy to do the things she loves the most, like swim, enjoy social events, and train with a ballet company.

Amanda just opened her very own dance studio, Dance Dreamworks, and is delighted to see her dreams come to fruition despite the struggles she faces and the obstacles she has had to overcome.

Faculty (cont.)

DANIEL H. TEITELBAUM, MD

**Professor of Surgery
CS Mott Children's Hospital
1540 East Hospital Dr
Ann Arbor, MI 48109**

Dr. Teitelbaum is a Professor of Surgery at C.S. Mott Children's Hospital, and the Medical Director for Homecare Services for the University of Michigan Health System. He is also the Program Director for Pediatric Surgery. He received his medical degree at Ohio State College of Medicine and trained in General Surgery at the Ohio State University Hospital and Pediatric Surgery at Columbus Children's Hospital. He began his work at the University of Michigan in 1992 and became a full Professor of Surgery in 2004.

Dr. Teitelbaum has Board certification in Pediatric Surgery, Surgical Critical Care, and General Surgery. He performs a wide range of general pediatric surgery, including surgery of the neck, chest, and abdomen. He has a strong interest and an international reputation in the surgical care for infants and children with Hirschsprung disease, colorectal anomalies, short bowel syndrome (SBS), and intestinal failure. Dr. Teitelbaum is the Co-Director of the Mott Children's Hospital Children's Rehabilitation Program (CHIR), which is one of the largest of such programs in the country and has led a number of novel efforts to promote the health and welfare of children who suffer from a number of intestinal disorders. He is also the Director of the Pediatric Colorectal Specialty Clinic. Dr. Teitelbaum is the President-Elect of the American Society of Parenteral and Enteral Nutrition (A.S.P.E.N.) and has a strong interest in promoting safe use of nutrition in infants and children.

Dr. Teitelbaum has an active research laboratory that focuses on many of the complications associated with nutritional care of patients and patients with SBS and intestinal failure. His laboratory also has an active interest in developing novel approaches to grow small bowel, including the use of stem cells and device development. His laboratory is funded by the NIH, Hartwell Foundation, FDA, and private industry.

ALLISON THOMPSON, RD, LDN, CNSC

**Clinical Dietitian Manager
BioScrip
1005 W 9th Ave, Ste B
King of Prussia, PA 19406**

After Allison Thompson graduated from Louisiana State University in 2000 with a degree

in Human Nutrition, she moved to Nashville, Tennessee, to complete her dietetic internship at Vanderbilt University Medical Center. She became a Certified Nutrition Support Clinician in 2005, and the concentration of her dietetic career has been on enteral and parenteral nutrition. She worked on the inpatient and outpatient nutrition support teams at Vanderbilt University Medical Center from 2004 to 2008. In 2008, she changed the focus of her career to home care nutrition management by joining the team at BioScrip. Her current position with BioScrip is Clinical Dietitian Manager, which includes both patient care and oversight of her team of dietitians.

ANN WEAVER

**Consumer Advocate
ThriveRx, Nutrition Division of BioRx
Chicago, IL**

Ann is a native Chicagoan with an undergraduate degree in psychology from Illinois Wesleyan University in Bloomington, Illinois.

Over the past two decades, Ann has devoted her time to advocating for parenteral and enteral consumers. She served as a Regional Coordinator for the Oley Foundation for several years and in 2014 received the Lyn Howard Nutrition Support Consumer Advocacy Award from the American Society for Parenteral and Enteral Nutrition.

MARION F WINKLER, PHD, RD, LDN, CNSC, FASPEN

**Oley Foundation Trustee
Associate Professor of Surgery, Alpert Medical
School of Brown University
Surgical Nutrition Specialist, Rhode Island
Hospital
593 Eddy St, NAB 218
Providence, RI 02903**

Dr. Winkler is an Associate Professor of Surgery at Alpert Medical School of Brown University and Surgical Nutrition Specialist, Department of Surgery and Nutritional Support Service at Rhode Island Hospital. She works with a multidisciplinary team in the care of hospital and home patients who need HPEN. Her research focuses on quality of life. She is a Past President of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). Dr. Winkler serves as Secretary of the A.S.P.E.N. Rhoads Research Foundation and is a member of the Scientific Advisory Council for SUSTAIN (A.S.P.E.N.'s Nutrition Care Registry) and the Board of Trustees for the Oley Foundation.

DONNA YADRICH, MPA, CCRP Research Operations Coordinator and Telehealth Interventionist

**HPN: iCare Mobile Technologies Assisting
Patients & Caregivers in Healthy Living
School of Nursing, University of Kansas
MS 4043 3901 Rainbow Boulevard
Kansas City, KS 66160**

Donna has been working on clinical research projects funded by the National Institutes of Health (NIH) for over twenty-five years at the University of Kansas Medical Center. She has experience with cancer patients and home parenteral nutrition (HPN) consumers and their families. For eight years, Donna has worked with Carol Smith, RN, PhD, FAAN; under her mentorship, Donna has authored and co-authored several peer-reviewed journal articles. Under the mentorship of Dr. Smith and Ubolrat Piamjariyakul, RN, PhD, she developed a data collection instrument to identify and tabulate out-of-pocket costs associated with chronic disease. This instrument has been used in Dr. Smith's NIH-funded projects for HPN and heart failure and its data has been published in peer-reviewed journals.

Donna earned a B.S. in Life Science and Physical Science (Kansas State University), a Master of Public Administration degree in Health Services (University of Missouri-Kansas City), and, since 1995, has been a Certified Clinical Research Professional (Society of Clinical Research Associates).

Working with Dr. Smith introduced Donna, her daughter, Audrey, and son, Peter, to the Oley Foundation, where finally a community was found with which they shared common ground. Although Audrey was not on HPN or HEN, she had a very serious and rare autoimmune syndrome that contributed to her death in 2011. Prior to her death, Audrey joined the State of Kansas' Youth Advisory Council for youth with special health care needs. To honor Audrey's unfinished work, Donna works to improve the experience of the chronically ill and their family members. She serves on several state and national initiatives and has founded a business named Audrey Spirit, LLC, to manufacture clothing for infants, children, youth, and adults with invasive medical devices. This year, xamtee™ therapeutic garments have been successfully tested at a U.S. News and World Report Best Children's Hospital.

Donna is the recipient of several awards and serves on many committees.

Research Prize / Scholarship

Nutrishare HomePN Research Prize

Sponsored by Nutrishare, Inc., Oley Silver Circle Partner

The Nutrishare HomePN Research Prize was established in 2007 to encourage clinical studies focused on improving the quality of life for homePN consumers. The 2014 prizes will be awarded to:

Michelle Park, BA

Stanford University School of Medicine
Palo Alto, California

*A Cognitive Aid “Central Line Care Card” for Central Line
Associated Bloodstream Infections in Pediatric Home Total
Parenteral Nutrition Patients*

Katelyn Chopy MS, RD, LDN

Rhode Island Hospital
Cumberland, Rhode Island

*A Qualitative Study of the Perceived Value of Membership
in the Oley Foundation by Home Parenteral and
Enteral Nutrition Consumers*

Brandi Gerhardt, RN, BAN

The University of Nebraska Medical Center
Omaha, Nebraska

*Successful Rehabilitation in Pediatric
Ultrashort Small Bowel Syndrome*

All three of these research papers will be presented during
Tuesday morning’s main session.

Kyle R. Noble Scholarship

Coordinated by Richard & Donna Noble

Kyle R. Noble’s enthusiasm for life affected many positively, and he is remembered widely with affection and admiration. Kyle passed away in 2006 at the age of eight. In 2007, the Noble family established the Kyle R. Noble Scholarship to recognize others who share the admirable qualities for which he will be remembered. In 2013, the Scholarship Committee selected Emily Koprucki.

Emily was born with megacystis-microcolon-intestinal hypoperistalsis syndrome, a very rare condition. As a newborn, she received her first G-tube (for tube feeding), as well as a central line for home parenteral nutrition (HPN). Looking back, Emily—now a high school graduate—says, “Despite the extra ‘appliances,’ I never felt my life was hindered in any way. I just ate differently, that’s all.”

For a while, Emily was able to consume enough calories and nutrients through tube feeding and by mouth that she could be weaned off HPN. But in seventh grade, she was put back on HPN and was unable to return to school for months due to low energy reserves, gastric pain, and severe weight loss. Thanks to Emily’s personal determination, she completed seventh grade with the help of a tutor.

In fighting to be able to return to school for eighth grade, Emily learned a great deal about self-advocacy. “Returning to school for eighth grade was a battle,” Emily writes. “At that point, I required continual infusions of HPN throughout the day. If I were to continue with my class schedule, I would have to infuse while in the physical school setting. The head of nursing for the school district was quite skeptical, and thought of us as overly ambitious in wanting to achieve this goal...After continuous battles for educational equality, we finally convinced her to hold a meeting with her staff. All the nurses for the district attended...I shared with them my daily routines of medicines, infusions, and procedures. I casually continued the discussion while simultaneously spiking a one liter bag of half normal saline with ease and effortlessly programming a ‘complicated’ pump as if it were a Game Boy.”

After this, Emily was allowed to attend school while infusing HPN. Just as important, Emily says, “This was the first time I really experienced what a difference I could make by advocating for myself.”

Emily has been an active member of the Oley community for many years. One of her high school teachers notes that Emily talks to him about some of the friends she has met through Oley activities. “Whenever someone she has come into contact with is having a difficult time, it weighs heavily on her; she is a tremendously caring person.”

Emily is also involved with an animal rescue program and is an avid horseback rider. “It is the most amazing high for me,” she writes, “and although it makes certain people concerned, it is an activity I can pursue while infusing hydration fluids.”

Complicated surgery in tenth grade caused Emily to miss much of another year of school, but she graduated with her class, and Emily now has one year of college behind her.

Past Recipients:

Mariah Abercrombie, Kailee Brown, Daulton Heisey, Alicia Hoelle, Chelsea Johnson, Nathan Natale, Tim Weaver, Emily Koprucki

Travel Scholarships

Many thanks to the following individuals and corporate sponsors for their generous support of scholarships for first-time consumer attendees.

Esther Ann Brown Adler Memorial Scholarship

“What could be bad about a weekend in Boston?” That’s how I rationalized my late wife Esther Ann’s suggestion that we attend something called an Oley Conference. I personally had no desire to spend a summer weekend at a convention talking about ostomy and J-tube products.

Much to my surprise, the convention was a wonderful experience! Many of the seminars and products did not apply to our situation but the camaraderie was overwhelming for Esther Ann and me. Here were people that truly knew what she dealt with on a daily basis. Other than a particularly rough excursion to Provincetown, my strongest memory of our first Oley Conference was a sense of relief that there were thousands of good people handling issues like ours and working on solutions.

Esther Ann and I both were very happy that we had made the decision to attend an Oley Conference and I am happy to support others in our position to do the same.

Jarol Boan, MD, MPH

As a practicing internist, I have seen patients on home PN or EN feeding who struggle with the long-term ramifications of their disease. The constant, unrelenting burden of “hooking up” every night takes a toll on self-esteem, work, and family relationships. Additionally, the financial burden of having a chronic disease cannot be underestimated, even if there is insurance coverage for the solutions. The multiple visits to a physician, increased cost of gas, and incidentals that are not covered by insurance add to the burden of home PN and EN feeding.

I strongly believe in the mission of the Oley Foundation to provide patient support for those affected, as well as educating physicians about home management. I have seen many patients helped by knowing there is an organization that is working on their side. The interaction between patients at an Oley conference is an important positive outcome for the attendees.

My gift to the Oley Foundation is intended to help patients and their families attend the Oley conference, and experience the encouraging exchange of ideas that occurs as a result.

Melissa Chaney Memorial Fund

I am Victor R. Chaney, the husband of Melissa Chaney, an HPN consumer and Oley contributor. Melissa passed away from natural causes on January 30, 2006. For more than nine years, Melissa battled pseudo-obstruction, polymyocitis, and mitochondrial myopath-transport chain deficiency. Over those years there were many drastic ups-and-downs. In the summer of 2003, Melissa learned of the Oley Foundation’s network of support and outreach. At that time Melissa’s health care management was less than adequate. Her weight was in a downfall—she was 5’1” and she averaged around 75 lbs.

After joining Oley, the change in her health care and overall quality of life was amazing. We credited the education and contacts she acquired at our first annual conference as the turning point in her health. Melissa’s wishes in life were that any memorial donations given after her passing would be directed to Oley. In keeping with those wishes, we established this travel scholarship so that others may have the opportunity she had in attending.

Friends of Robin Lang Memorial Travel Fund

To honor the memory of Robin Lang, several of her friends pooled their funds to continue a tradition that meant a great deal to Robin: getting more HPEN consumers to the Oley conference. As Robin explained once, “When I was born, I was bitten by the travel bug. When I became an HPNer I thought that bug was smashed into the windshield of my car. About one or two years after becoming an HPNer, I was able to attend Oley meetings. I learned so much, my life was forever changed. I have driven across the country (all the while mixing my PN). I’ve traveled to the Caribbean and made two trips to Europe. I’ve learned life-saving techniques, diet information, cutting-edge practices to keep me and my lifeline safe, and so much more. Most importantly, I learned that I am not alone. I have made many friends who have brought me a great deal of happiness. I’m so grateful to have the opportunity to help others have similar positive experiences.”

Corporate Support for Travel Scholarships

NPS Pharma
Short Bowel Syndrome Foundation
ThriveRx



Travel Scholarships (cont.)

Bruce F. Groeber Family

Bruce Groeber was an avid fan and regular attendee of the Oley annual conference. He never missed a conference after attending his first in 1988 until his death in March of 1997. Even though Bruce was on HEN for nine years and on HPN for an additional nine years due to malabsorption, he loved to eat and drink. He also loved boats and the water, computers and talking to people—most of all, though, he loved his family. Bruce and his wife Bobbie (still active in Oley as an Ambassador), have five children. Bruce also has several grandchildren now.

The Bruce F. Groeber family feels it is important to sponsor a travel scholarship to the annual Oley conference because of what the conference has provided our family. The conference provides the opportunity to get together with others who have similar issues and concerns. It provides the opportunity to learn about new ideas and information. People leave the annual Oley conference knowing that they are not alone, feeling empowered and more positive about their life. They are aware of how much more information they have than when they started. The Bruce F. Groeber Travel Scholarship hopes to honor the joy Bruce found in the companionship with other Oley families by supporting others in their efforts to attend the conference.

Carol Ireton-Jones, PhD, RD, LD, CNSC, FASPEN, FAND

It is my pleasure to donate to the patient travel grant funds for the Oley Annual Conference. As a professional attendee, speaker and volunteer, I know how important this conference is for consumers. However, until I read the consumer travel grant applications, I did not realize that the ability for a consumer to attend this meeting is potentially life changing—whether they are new or long-term, young or old, enteral or parenteral! Too many people are without the support of another person “just like them.” Finding that person is one of the key benefits of attending.

Carol & Jack Leibee

In April 2005, the Leibees' lives changed dramatically when Jack was diagnosed with short bowel syndrome. Complications arose frequently. They were astounded by the lack of information available to them. As Jack puts it, “soon we had more questions about my care than answers.” Fortunately they were put in touch with the Oley Foundation. Jack continues, “Oley has provided my wife and me with critical information that has allowed us to make informed decisions about how we treat my condition.” They also found support through Oley conferences. “Talking face to face with other families and health care specialists at these meetings has proven invaluable. We learned tips that made an immediate and lasting difference in my health and quality of life,” he adds. The Leibees are sponsoring a travel grant so they can share this valuable experience with another consumer.

Judy Peterson, RN, MA

Judy Peterson is a long time Oley member, former Oley volunteer Regional Coordinator in the San Diego area, and has attended several Oley conferences. She trained as a nurse, and later received a masters degree in pastoral counseling. Judy has short bowel syndrome secondary to Crohn's disease. She recognizes the importance of consumers keeping themselves well informed and is committed to helping consumers realize the positive elements of being on nutrition support.

Janet Platt & Christopher Hlatky

We are sponsoring a travel grant for this year's Oley Foundation Consumer/Clinician Conference because we strongly believe in the positive impact attending the conference can have. Several years ago Janet's brother got his first tubes. We were all scared and depressed. What did this mean for his quality of life? Would he be able to work? What was his life expectancy? The doctors and nurses at the hospital seemed almost as clueless as we were. Then a social worker mentioned Oley casually in passing. I found out the annual conference (that year in Saratoga, NY) was only a few weeks later. I signed Janet's brother and me up and practically dragged him there from the hospital!

From the moment we arrived, we found a warm, supportive, and INFORMED group of people. We met lifelong tube users who were in college or working full-time, people who had families, people who, in general, were experiencing an excellent quality of life. We got so many questions answered. We learned about different kinds of tubes and pumps, different kinds of care providers and insurance issues. We left feeling much more positive about life with feeding tubes.

Having Oley around to support and inform is priceless. Helping other tube users get the support they need is important to us.

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs all year long. Corporate relationships also strengthen our educational and outreach efforts. For their continued interest and strong commitment we remain grateful.

PLATINUM LEVEL PARTNERS

(\$70,000)

BioScrip, Inc.

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(\$50,000)

Coram CVS/specialty infusion services

Covidien

ThriveRx

SILVER CIRCLE PARTNERS

(\$30,000)

Boston Scientific

NPS Pharma

Nutrishare, Inc.

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Baxter Healthcare

Fresenius Kabi USA

BENEFACTOR LEVEL PARTNERS

(\$10,000)

Abbott Nutrition

Kimberly-Clark

Nestlé Health Science

Walgreens Infusion Services

PATRON LEVEL PARTNERS

(\$5,000)

Applied Medical Technology, Inc.

Nutrishare Canada

Horizon Society Members

Ensuring the Future of Oley

Many thanks to those whose commitment and dedication to the Oley Foundation has led them to arrange a planned gift to help ensure continuing support, service, and advocacy for HPEN consumers and their families.

Felice Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Cotter
Jim Cowan
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
Dale & Martha Delano
Tom Diamantidis, PharmD
Gail Egan, MS, ANP
Selma Ehrenpreis
Herb & Joy Emich
Jerry Fickle
Don Freeman
Linda Gold
Linda Gravenstein
Deborah Groeber

The Groeber Family
Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD, PhD, FACP
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Laura Matarese, PhD, RDN, LDN, CNSC,
FADA, FASPEN
Kathleen McInnes
Michael Medwar
Meredith Nelson
Nancy Nicholson

Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
Judy Peterson, MS, RN
Clemens Pietzner
Beverly Promisel
Abraham Rich
★ NEW! Wendy Rivner ★
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schesnol
Doug Seidner, MD, FACG, CNSP
Judi Smith
Steve Swensen
Cheryl Thompson, PhD, RD, CNSC, &
Gregory A. Thompson, MD, MSc
Cathy Tokarz
Eleanor & Walter Wilson
Marion & Larry Winkler
James Wittmann
Patty & Darrell Woods
Rosaline Ann & William Wu

Join Us!

If Oley was there for you and your family in a substantial way, please consider becoming a member of the Oley Foundation Horizon Society.

This is our best chance of making sure Oley is there for the next consumer, and the next.

Joan Bishop and Roslyn Dahl can answer your questions this week, or speak to you at any time at (800) 776-OLEY or bishopj@mail.amc.edu or dahlr@mail.amc.edu.

“Oley holds a special place in my heart, and its future security is important to me. It’s an honor and a privilege to be a part of this group that shares my passion.”

— Joan B.

Ribbons & Dots

You've probably noticed several people milling about the conference wearing ribbons and stickers on their badges. To unravel the mystery, below is a color-coded guide to their significance. Colored stickers ("dots") can be used to identify the diagnosis (or diagnoses) and nutrition therapy (or therapies) your family has experience with—making it easier for you to connect with others with similar experiences. Pick up ribbons and stickers at the registration desk.

Ribbon Color	Indicates	Sticker Shape/Color	Diagnosis
Bright Green	First Time Attendee...please make them feel welcome!	☺ red	Short bowel syndrome
Red	Award Winner	☺ purple	Motility disorder
Brown	Award Nominee	☺ orange	Swallowing disorder
Black	President	☺ pink	Inflammatory bowel disease
Maroon	Conference Co-Chair	☺ yellow	Other
Ocean Blue	Oley Board Trustee		
White	Past Board Trustee	Sticker Shape/Color	Therapy
Turquoise	Conference Chair	★ silver	Parenteral nutrition (PN)
Teal	Faculty	★ blue	Enteral nutrition (EN)
Kelly Green	Exhibitor		
Red/White/Blue	Oley Ambassador	Sticker Shape/Color	Status
Hot Melon	Conference Volunteer	♥ red	Caregiver/spouse/family member
Hot Orange	Inspire Member		
Eggplant	Ask Me, I'm a Dietitian		



Want to meet your Inspire friends?

Add an orange "Inspire Member" ribbon to your name badge and introduce yourself to others with the ribbon.



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ENDO-249711-AA June 2014

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A New Twist on Enteral Connection Safety



Recently, the International Standards Organization created ISO CD 80369-3 defining a safe design for an enteral feeding connector. Covidien, in collaboration with companies across the industry, has helped to develop the ENFit Twist Connection System and the Stay Connected Initiative. By adopting ENFit connections, the complete Kangaroo™ portfolio will have the added safety of an internationally accepted standard for safe enteral connections.

**See what's new from Kangaroo™
at the 2014 Oley Conference**

www.SafeEnteralConnections.com

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Fresenius Kabi USA is a global health care company that specializes in medicines and technologies for infusion, transfusion and clinical nutrition. Our products - from specialized injectable pharmaceuticals and nutrition solutions to medical technologies used in blood collection, cell therapy and infusion medicine - are used to care for critically and chronically ill patients. We have in depth expertise and a global network in manufacturing and science. We offer award-winning service to medical professionals across the United States. Our roots in health care go back more than 100 years. Our people are committed to a singular purpose: *caring for life.*

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Visit ThriveRx's Rehydration Station

Drop by the Rehydration Station in the exhibit hall to test taste and learn more about Oral Rehydration Solutions. We will be open Tuesday and Wednesday during breakfast and lunch and on Thursday before the Walk-A-Thon.

ThriveRx, a division of BioRx LLC, is a national provider of home TPN and Enteral services. Our mission is to provide education which empowers our consumers.

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“The MIC-KEY* was huge in terms of improving the quality of my life.”

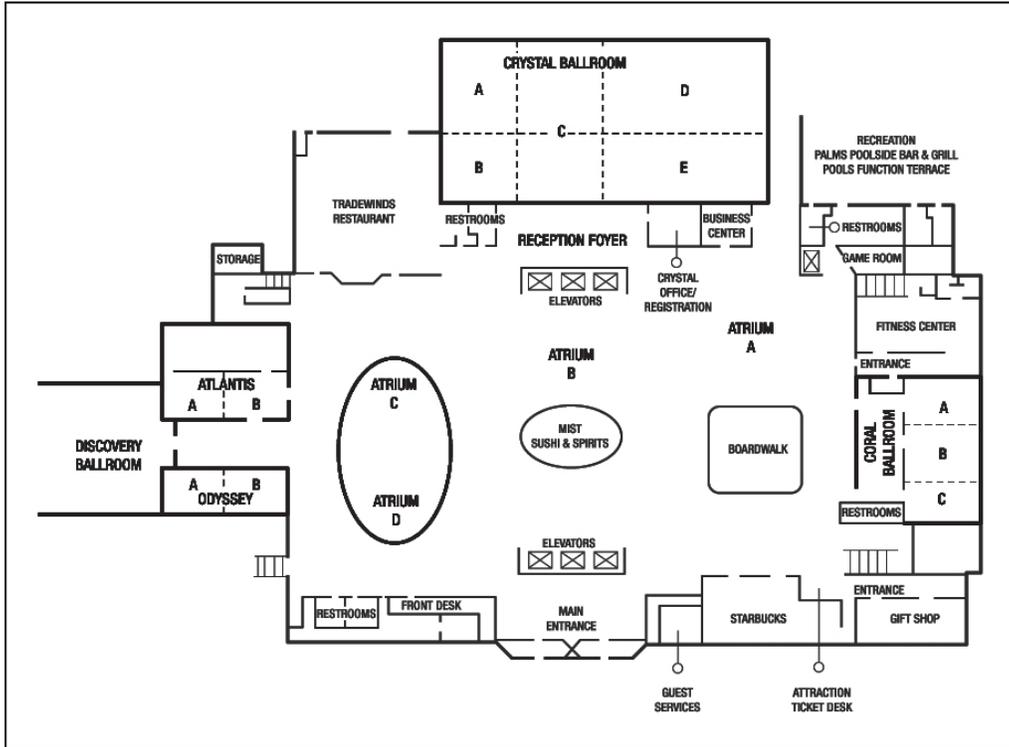
-Rick Davis

Stop by our table
at the OLEY Conference.

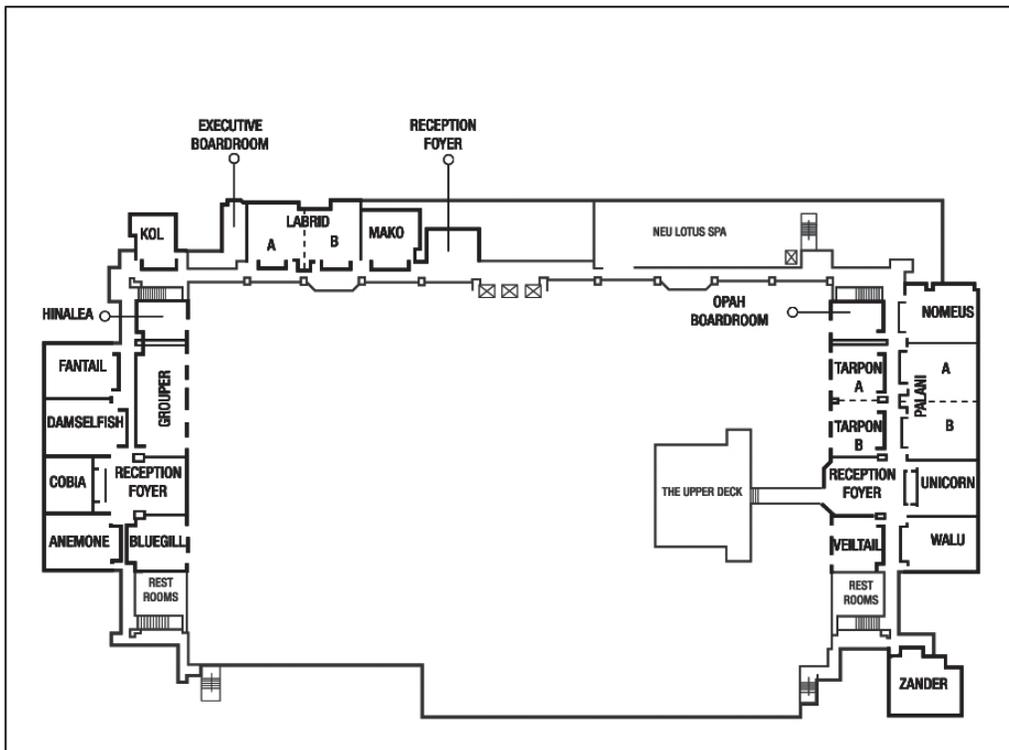
 **Kimberly-Clark**

Map of Renaissance Meeting Rooms

First Floor



Second Floor



Note: To access the meetings rooms on the second floor, use the elevators at the back of the Atrium, near the Crystal Ballroom. (The elevators by the hotel's front entrance do not stop on the second floor.)

