

What's Inside:

**Tube Talk: Securing
a Tube** Page 3

**Oley's Newest
Ambassadors: Hadar
and Tiffany** Page 4

The Bright Side Page 4

**Parents: Help
Researchers
Understand Home
Health Care** Page 5

**2017 Annual Donor
List** Pages 6–8

**Update on IV Fluids
Shortages** Page 9

**Oley at 2018 ASPEN
Meeting** Page 9

**Oley Equipment
Supply Program
Update** Page 12

Donor News Pages 14–15

Oley Calendar Page 16

LifelineLetter

Living with home parenteral and/or enteral nutrition (HPEN)

Treatment Options for Gastroparesis

Thomas Abell, MD

This article was adapted from the transcript of a webinar Dr. Abell presented for the Oley Foundation in July 2017, at the Oley conference in Old Greenwich, Connecticut. This and another webinar by Dr. Abell were recorded and can be viewed at www.oley.org.

I have been interested in GI motility disorders, including gastroparesis, for fifty years. My initial interest stemmed from my observations of migraine-related nausea and vomiting in friends and family members. While studying at Yale University in 1968, I was assured that these disorders were psychosomatic, that is, physical symptoms caused by psychological factors. I set out to see how this could be possible. As you'll see, I found out they are not psychosomatic; they are organic disorders.

Symptoms of Gastroparesis

The vast majority of patients with gastroparesis (Gp) have one or more of these symptoms: nausea, vomiting, abdominal pain. They may also have bloating (distension) and/or loss of appetite (anorexia). They may have

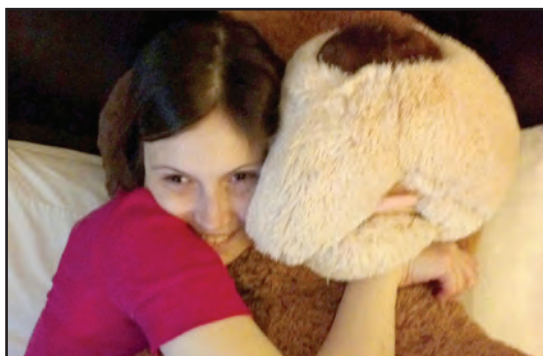
constipation and/or diarrhea, or fecal incontinence; urinary hesitancy and/or urinary frequency; or interstitial cystitis, which is an inflammatory disease. Other patients have autonomic symptoms, such as dizziness, cold intolerance, and/or heat intolerance.

About half of the patients we see with severe disorders have migraine headaches. They may have muscle pains, and are often diagnosed with fibromyalgia. Or they may have autoimmune diseases. Some have overly flexible joints. Others may have seizures or other neurologic disorders.

Some patients have symptoms that come in cycles: they do well for a few days, and then they don't do well for a few days. Many have a family history of symptoms.

What are all these symptoms from? Many are seen with acute illness or viral infections, but with Gp, they may be recurrent or chronic. Unfortunately, most providers, including myself, never learned about this

Gastroparesis, cont. pg. 2 ➤



Tiffany with the stuffed dog she got at an Oley auction.

Being Me

Tiffany Dodd

Wondering what an Oley conference is like? Tiffany, a new Oley Ambassador, wrote this blog post about the 2013 Oley conference, where she felt she could be herself (May 2015, www.tiffadpositivity.blogspot.com, adapted with permission). Read more about Tiffany on page 4.

In 2013, Javier and I went to Cape Cod on a "vacation" to a medical conference put on by the Oley Foundation. I was really hesitant at first because "medical conference" and "vacation" in my books did

Being Me, cont. pg. 13 ➤



**June 24–27, 2018
Peabody Memphis**

Some of the things you should know about the 2018 Oley Consumer/Clinician Conference:

- **Rooms at the Peabody** are \$164/night for general attendees, and \$229/night for exhibitors (cutoff date June 1). See www.oley.org/AnnualConference for important details and a direct link to reserve your room. Book early. We've sold out in past years.

- **A limited number of \$600 travel grants** are available for consumers/caregivers (one per family, please) who will be attending the Oley conference for the first time. If there are still grants available on May 24,

Oley Conference, cont. pg. 14 ➤

LifelineLetter

January/February 2018
Volume XXXIX, No. 1

Publisher:

The Oley Foundation
Albany Medical Center, MC-28
99 Delaware Avenue
Delmar, NY 12054
(518) 262-5079, Fax: (518) 262-5528
www.oley.org

Executive Director:

Joan Bishop • BishopJ@amc.edu

Editor, LifelineLetter; Director, Community Engagement:

Lisa Crosby Metzger • MetzgerL@amc.edu

Communications & Development Director:

Roslyn Dahl • DahlR@amc.edu

Administrative Assistant:

Cathy Harrington • HarrinC@amc.edu

Executive Assistant:

Andrea Guidi • andreaguidi.oley@gmail.com

Program Associates:

Philip Kellerman • philkellerman.oley@gmail.com
Mary Wootten • marywootten.oley@gmail.com

Science & Medicine Advisor:

Darlene Kelly, MD, PhD

Medical Director/Co-Founder:

Lyn Howard, MB, FRCP, FACP

Oley Advisory Council:

Jane Balint, MD; Lynda Bosworth; Alan Buchman, MD, MSPH, FACP, FACC, AGAF; Frances Culp; Marcia Denenholz; Terry Edwards; Jocelyn Hill, MN, CVAA(c), OCN, CRNI, VA-BC; Kishore Iyer, MBBS, FRCS, FACS; Swapna Kakani; Barbara Kapuscinska Kelly, MD; Sue Koprucki; Vanessa Kumpf, PharmD, BCNSP; Jack Leabee; Laura E. Matarese, PhD, RDN, LDN, CNSC, FADA, FAS-PEN; David F. Mercer, MD, PhD, FRCS; Russell J. Merritt, MD, PhD; Ann Michalek, MD; Vicki Ross, RD, PhD, CNSC; Trish Skiendziel, RD, LD, CNSC; and Ezra Steiger, MD, FACS, FASPEN

Oley Board of Trustees:

Bob and Mary Smithers, Co-Presidents; Beth Gore, PhD, MBA, Vice President; Joy McVey Hugick, Secretary; James Senese, BS Pharm, MS, Treasurer; Lynn M. Anderson, LLD; Rhonda Arends; Lillian Harvey Banchik, MD, FACS, CNSC, FASPEN; Elizabeth Bond, RN; Debbie Fox, MS, RD, LD; Shirley Huang, MD; Jerry Mayer; Manpreet Mundi, MD; Laurie Reyten, RN, MN; Kelly Tappenden, PhD, RD

Subscriptions:

The LifelineLetter is a bi-monthly newsletter sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Editor at the address above.

Gastroparesis, from pg. 1

in medical school, training, or practice; thus they may not value these symptoms, or the illness behind them. Patients have taught me that this leaves them suffering from what I call the five Ms: miserable, misunderstood, misdiagnosed, mismanaged, and mistreated. Hopefully, those days are largely behind us.

Quality of Life with Gp

I've been impressed at how little we know about Gp, as well as how much patients are able to tell us, if we'll just listen. I've been impressed, too, at how much suffering, which is now called the "disease burden," exists.

In the 1990s, my colleague Dr. Teresa Cutts, a psychologist, and I held nearly a hundred focus groups for patients with the symptoms of gastroparesis. Over the last twenty-five years we've looked at the data collected, much of it prospectively.

One article we published based on this data looked at quality of life (QoL) with Gp using the SF-36, a standard generic tool that helps rate QoL. The SF-36 allows you to look at physical functioning, pain, social functioning, and general health. Based on a large sample of people with Gp, we found there are a lot of problems with physical and social functioning, and a lot of pain and general health issues. (See figure 1.)

We have learned several things since we started these groups: (1) the team approach to Gp is crucial for helping patients; (2) the autonomic nervous system is part of the illness, and the GI tract may not be the only system that is involved; (3) providers often underestimate the effect of the illness on QoL; (4) for some patients, Gp is associated with increased levels of anxiety and depression, likely due to the trauma of the illness (as opposed to being the cause of the illness); and (5) well-intentioned providers often make things worse while trying to make things better.

Gp Research Consortium

Federal involvement in Gp is quite important. The National Institutes of Health (NIH) Gp Clinical Research Consortium (GpCRC) was set up in response to patient needs, with patients contacting their congressmen and senators and NIH saying, "We need help." The impetus behind the GpCRC was literally a discussion in a patient's kitchen; it is now in its eleventh year.

The GpCRC has defined the disease burden by providing descriptions, diagnoses, details of illness, and distinctive pathophysiology of Gp. The NIH GpCRC has also helped stimulate concomitant interest in Gp at the FDA and

Gastroparesis, cont. pg. 10

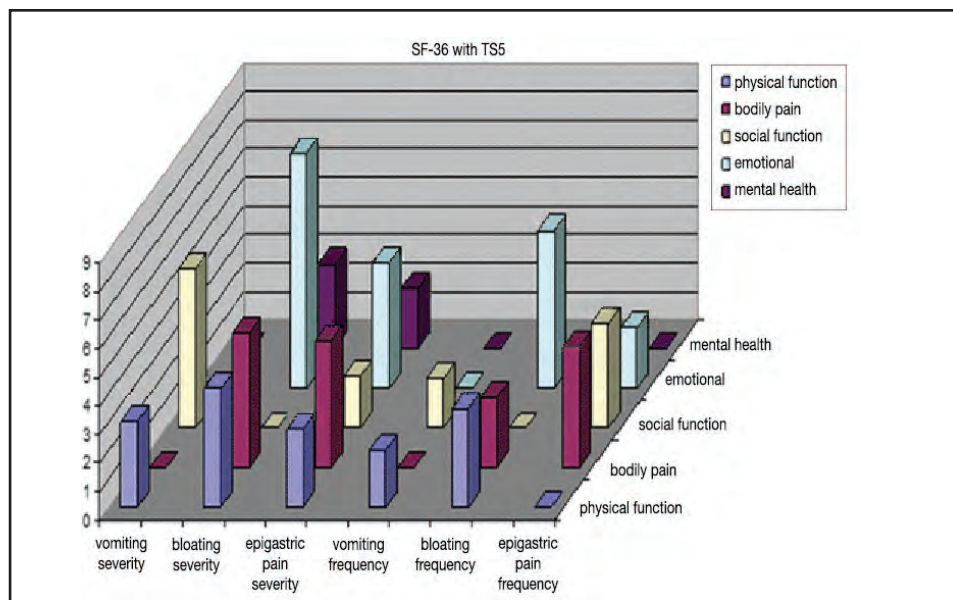


Figure 1. GI total symptom scores correlated with SF-36 measures from a sample of patients with the symptoms of Gp.

Adapted with permission from Cutts et al, *Twenty-five years of advocacy for patients with gastroparesis: support group therapy and patient reported outcome tool development*, BCM Gastroenterology (2016) 16:107 DOI 10.1186/s12876-016-0523-3

Tube Talk

Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@amc.edu. Information shared in this column represents the experience of the individual and should not imply endorsement by Oley. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.



Options for Securing Tube

When I first got my tube, I just let the tube hang out and down. That wasn't good.* Next, I left the Y extension attached and hung it with a slip connector on my dog tag chain. That still works—at times.

After I got my second tube, I got all my supplies thru the VA, and they included the Surgilast® [Tubular Elastic Dressing Retainer]. It works much better and can be stretched over the tubing and connectors as desired. It comes in sizes small enough to fit your pinky finger to large enough to fit the trunk of a very large person; sizes 1–22. I got size 11.

I hope the pictures [on right] tell the story.

—Jim V.

*Editor's note: Excessive movement or tension at the exit site can cause enlargement of the tube tract, irritation, or ulceration; accidental or excessive pulling of the tube; and other problems. See our "Tube Feeding Troubleshooting Guide," available at www.oley.org/HEN_LandingPage (under "Tools"), by calling (518) 262-5079, or through the Oley store (no charge).

Right: Surgilast prevents Jim's tube from dangling and getting caught on things.



Left: One of Jim's solutions was to hang the end of his tube on his dog tag chain.



Above: Surgilast helps hide the tube under Jim's shirt.



Real Food for People With Feeding Tubes is Possible!



Real Food Blends now offers 5 different 100% real food meals for people with feeding tubes!

*No corn syrup or preservatives * ~330 calories per meal * Covered by many insurance plans * Great for kids & adults * No refrigeration required

For more information, visit www.RealFoodBlends.com

GLEASON.

LIVE WITH PURPOSE.
LOVE WITH PURPOSE.

To find out more about Steve Gleason, be sure to visit: facebook.com/mymickeytube



HALYARD

LEARN MORE ABOUT
MIC-KEY* G Low-Profile Feeding Tube

For more information, please visit www.mic-key.com

LIKE US ON
FACEBOOK!

*Registered Trademark or Trademark of Halyard Health, Inc. or its affiliates. © 2018 HYH. All rights reserved.

Photo by Robert X. Fogarty

Welcome Oley's Newest Ambassadors

Meet Hadar and Tiffany, our newest Oley Ambassador volunteers. Ambassadors are available to help get the word out about Oley and to help consumers and caregivers overcome some of the challenges presented by enteral (tube feeding) and/or parenteral (IV) nutrition. Ambassadors are listed at www.oley.org under "Meet Consumers/Patients," or call (518) 262-5079 for a list. Contact them with your questions, or for an understanding ear. Please note that Oley Ambassadors should not be contacted for solicitation, marketing, or research purposes.

Join us in welcoming Hadar and Tiffany!

Hadar Birger-Bray

Hadar was born and raised in Israel. She served in the Israeli Army and moved to the United States in 2006. She says, "I'm married to a wonderful wife and have two kids. I'm a full-time power wheelchair user and suffer from a progressive neuromuscular condition that affects my muscles, my GI tract, and other systems in my body. In addition to coping with my own GI issues, my daughter suffers from gastroparesis as well. I work as a Hebrew and Judaica teacher and try to be involved with the community as much as I can."

In 2016, Hadar was hospitalized after going through balloon dilation and Botox injection to the lower esophageal sphincter. After being NPO for a while and not being able to tolerate any food or drink without vomiting, she ended up with a G-tube that quickly was changed



Hadar Birger-Bray

to a G-J tube as she wasn't able to tolerate any feedings through the G. "My experience with feeding tubes and being on home enteral nutrition (HEN) has been full of ups and downs," says Hadar. "It was my source of nutrition and what kept me alive, but on the same token it was the reason behind my being constantly admitted to the hospital every time the balloon popped. In late 2017, I found myself being admitted once again with balloon malfunction. This time something wasn't right, and I

was not able to tolerate feedings. After being without nutrition for two weeks I started my new relationship—this time with home parenteral [IV] nutrition (HPN)." Hadar has a PICC line, and also still has her G-J tube. The G portion of the tube is used for twenty-four-hour drainage and the J portion is used to administer meds.

Hadar says, "I am more than happy to be here for anyone who wishes to talk and process what they go through. In the future, I hope to start a support group in my area for anyone who has been affected by HEN or HPN."

Hadar lives in Blue Bell, Pennsylvania. You can contact her by email at hadarbirger@hotmail.com.

Tiffany Dodd

Tiffany is thirty-three years old (2018) and lives in Framingham, Massachusetts. She is the second oldest of five children, with, she notes, "a very supportive single mother who played the role of both mother and father." Tiffany lives with her mother and fiancé, Javier, in the home she was raised in.

Tiffany lives by the motto, "Live every day as if it's your last; take advantage of the good days and find good in the bad days." To get through good or bad days, she enjoys photography, scrapbooking, coloring, and writing her blog. The blog, she explains, helps her share experiences and express her feelings; she hopes it inspires others. (See the front page for an edited version of one of Tiffany's blog posts, where she talks about her experiences at the Annual Oley Consumer/Clinician Conference in 2013.)



Tiffany Dodd

Tiffany is also an avid New England sports fan—cheering for the Red Sox and the Patriots—and she loves spending time with her family, which includes six nieces and nephews, and friends.

Although Tiffany had some medical conditions growing up, it wasn't until she was

The Bright Side

To life, whatever it is, has a positive side. You wake up in the morning—you are already fortunate. You are capable to open your eyes and see the sunlight—your world is almost complete.

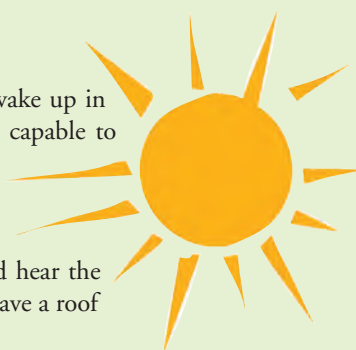
Sometimes, I have to remind myself how good the world is. How wonderful it is to wake up and hear the chirping of the birds. I realize how lucky I am to have a roof over my head, and a warm supportive family.

Don't misunderstand me, life is not simple. I'm not saying that my life is harder than others, but I can definitely say that life puts many road bumps in front of me.

I don't ignore the bumps—I don't live in a delusion. I simply choose to focus on the good that the world gives. I believe that everything is a matter of attitude. If you focus on the positive, your day will be much lighter. If you decide to...see everything in the negative, your life will be miserable. Here I can add a mantra: "Always look on the bright side of life."

Try it next time you feel that your day is full of difficulties. You might find out quickly that life is much more beautiful when you focus on the good in our world.

From Hadar's blog, www.fromtheheightsofthechair.wordpress.com.



seventeen that she was diagnosed with primary immunodeficiency and hypogammaglobulinemia. After starting antibiotic therapy as well as IVIG, she did well enough to attend college. Her medical struggles began after she had graduated from college and joined the workforce. Because of her weakened immune system, her stomach was attacked by a virus; soon after she was diagnosed with gastroparesis. Currently, Tiffany deals with asthma, severe anemia, allergies, cardiomyopathy, postural orthostatic tachycardia syndrome (POTS), migraines, and blood clots.

Tiffany lives with a J-tube that is used for medications, a G-tube that is on twenty-four-hour vent, and a trans-lumbar central line through which she receives multiple IV therapies. She's had multiple surgeries, including the placement of several central lines and feeding tubes and a roux en y (which was unfortunately unsuccessful). Over the last

six years, she has tried tube feeds via both the J- and G-tubes, but has not been able to tolerate them. She is on home parenteral nutrition (HPN) twelve hours every day, as well as extra IV hydration each day.

In college, Tiffany's goal was to end up in the juvenile delinquency field to help kids who were heading in the wrong direction. Since she has not been able to pursue that goal, she hopes instead to inspire or help people who are alone or feel like they have no one to turn to. Before attending her first Oley conference, Tiffany says she felt defeated because nobody could understand what she was going through. After attending her first Oley conference, she found others that could relate. Now, after having attended multiple conferences, she feels like she is part of a special group. She hopes as an Oley Ambassador she can introduce Oley to people who feel the way she did before she found the organization. ¶

Parents: Help Researchers Understand Home Health Care

Pediatricians from Johns Hopkins Hospital and Children's National Medical Center are conducting a research study entitled, "Home Health Services for Children with Chronic Critical Illness: Stakeholder Perspectives" (IRB00145711; Principle Investigator: Renee Boss, MD).

The researchers are recruiting parents with experience with pediatric home health care (home nursing, home medical equipment, parenteral nutrition, physical/occupational therapy, etc.). They are **particularly interested in talking with parents who have experience with home health care for a child with chronic and complex medical conditions.** The researchers would like to **interview these parents for thirty minutes (by telephone) to learn more about their perspective.** The researchers' primary goal is to describe the barriers and facilitators to home health services for children with serious medical conditions.

If you are willing to participate in this interview, please email Dr. Boss at rboss1@jhmi.edu or call (410) 614-5635 to let them know. Prior to the audiorecorded interview, they will provide you with a list of the interview questions so that you will have the opportunity to consider your responses. At the time of the interview, they will review with you the study objectives and the role of research participants. They will ask you to provide oral consent for the interview. **Upon completion of the interview you will receive a \$50 gift card for your participation.**

The researchers believe that the information gathered in this study will be useful in expanding novel approaches to care for these children and their families. They very much appreciate your perspective regarding pediatric home health services, and look forward to learning more from you.



Wear THE CAP!



**Support the
#tpnstrong message
of empowerment by
wearing THE CAP!**

To get yours go to
www.hometpn.com



Answer a question & choose a color,
it's that easy.

Nutrishare®
1-800 Home TPN
www.nutrishare.com

Thank You for Your Support in 2017!

The following list represents everyone who contributed toward Oley's efforts in 2017. We also want to thank those who are not listed below, or special event, we've created a separate list, which can be found on page 8.

Generous Gifts Without Bounds (\$5,000+)

\$10,000 Jane Balint, MD, in honor of the late John Balint, MD, founding Oley Trustee
\$7,220 Jack and Carol Leibee
\$5,100 Anonymous

Ambassadors (\$2,000–\$4,999)

Leah and Steven Atkinson
Geoffrey O. Burney
Paul DeBarbieri
Dale and Martha Delano, includes matching gift from the GE Foundation
Darlene Kelly MD, PhD***

President's Circle (\$1,000–\$1,999)

Anonymous, in memory of Dr. John Balint
Anonymous, in memory of James Nagin, father of Lyn Wolfson**
Lillian Harvey Banchik*, MD, FACS, CNSC, FASPEN
Mr. Richard Dillon
Tiffany Dodd**
Jerry and Dotty Fickle
Jill Johnke, MBA, RD
Nancy and Peter Kudan, in honor of Mike Sherels; and in memory of Shirley, Arnold, and Fred Klein Network for Good

Benefactors (\$500–\$999)

Eva Abel, in honor of "my amazing sister, Emma Tillman"
Amherst Jr. A Ramblers 97
Anonymous, in honor of Ruby "Kick Ass" McDonald on her first birthday
Jarol Boan, MD
BriovaRx Infusion Services
Dr. John and Carol Broviac
Frona Brown
Groeber family via the Community Foundation of the Greater Capital Region
Joanne K. Hilferty
M. T. Hirschler, in memory of Patricia Brown, RN, MSN
Janet and Christopher Hlatky
John D. Hutchinson and Dr. Kathy Platoni
Kathy and Chris Mannino, in memory of Clarence "Oley" Oldenburg
Mary Miller, in honor of Barbara Klingler**
Alyce Newton
Melinda Parker, MS, RD, CNSC
Lynn and Kurt Patton

Fred Reuning and Janis Callison
Soleo Health
Marsha Stieber, MSA, RD
Debra Gilbert Taylor and James Taylor
Santhi and Kanaka Vege, in honor of Dr. Darlene Kelly***
Michael and Ann Weaver, includes matching gift from FM Global Foundation
Dr. John and Cornelia Wesley

Sponsors (\$250–\$499)

Thomas Abell, MD
John and Heidi Andolina
Anonymous
Anonymous, through United Way of Southern Nevada
Susanne and David Appel, in honor of Rebecca Appel and Daniel Appel, and "with great appreciation to Oley"
Jon Becker
Lynda Bosworth, in memory of Easter Gower, Edy Bosworth, Rick Hernandez, and David Nappo; in honor of the birth of Eloise Baumann and the strength of Jennifer Blons
Rick Davis
Rebecca Edwards
Gail Egan, MS, ANP
Jeff Fairbanks
Lenore Heaphey and John Worthley
Rose** and Jeff Hoelle
Swapna Kakani**, includes donations for the Chicago Marathon fundraiser
Barbara Klingler**
Brian Koenig, in memory of Kyle Noble
Adam Koncius, in honor of Aidan Koncius
David McGee
Ron and Lisa*** Metzger, through United Way of the Greater Capital Region
Michael Mondello
Christy Noland
Carol Rees Parrish, MS, RD
James and Susan Penzner
Francis and Joan Scheib, includes matching gift from the GE Foundation
Karl Schten, in honor of the Erik Schten family
Douglas Seidner, MD, AGAF, FAGC, FASPEN, CNSC
David Seres, MD
Steve and Edith Swensen
ThriveRx, Inc., in honor of "our awesome ThriveRx employees and team walking in the Walkathon"; in memory of Samantha Bye, Robert Pacillo, and James Silveira
Ruth Zommick, in honor of Dr. Lillian Banchik*, from her mom and sisters

Patrons (\$100–\$249)

Sharon Alger-Mayer, MD
Amazon Smile
Anonymous
Anonymous
Anonymous, in honor of Clifton Dodge
Anonymous, through United Way of the Greater Capital Region
Rhonda Arends*
Arthur R. Benanti
Hadar Birger-Bray**
Marcia Boatwright RN, CRNI, in memory of Lloyd Mollenkopf
Buddy Bond
Gail and Chuck Brenenstuhel
Neil Brenner
Jean D. Brown
Delmar Burkett, in honor of Rick Davis
Stanley Caulder, in memory of Zoe Allison Hartley
Steve Cohen
Terese Connolly, in honor of Philip DiVito
Gene Costa, in honor of Mary Ellen Costa
Dean and Linda Crowley, MS, RD, CDN, CNSC, in memory of Leslie Noyes; includes matching gift from the GE Foundation
Marcia** and Howard Denenholz, in honor of Marcia's birthday and Marcia's recovery
James and Suzanne Douglas, in honor of Tanner Shuman
Diane Duke
Mr. and Mrs. John Eidem, in memory of Charlie Eidem
Jeffrey and Joanne Ellena, in memory of Donald Lester Norton
Laura Ellis, PhD, RD
Herb Emich
Beverly Engle, in memory of Donald Engle
Harry and Ruth Ann Forgan
Todd Friedman
Mary Gergely
Barry and Martha Ginsburg, in honor of the recovery of Natalie Ginsburg
Meagan Glover
Shannon Goldwater
Stuart Gordon, in memory of Irmagail Gordon
Joseph Goyette
Greater North Houston Dietetics Association
Elizabeth and Joseph Greenberg, in honor of the Erik Schten family
Bobbie Groeber
Deborah Groeber, in memory of Bruce Groeber
Lyn Howard, MB, FRCP*

Brad and Joy Hugick*, **
Janet and Frank Ivory-May
Harlan Johnson, in memory of Mary Patnode
Bhavani Kakani
Susanne Karacki, in memory of Larry Karacki
Janice Myers Knight, in honor of "all those I pray for and love who depend on feeding tubes"
Pam Kruger, PhD, through YourCause
Ann LaBortz
Thomas and Christine Lally
Christopher and Larissa Lang, in memory of Robin Lang
Timothy Lang, in memory of Robin Lang
Joan Lavers
Brad Lyon
Cindy and Tom Macko, in memory of Clarence Oldenburg
Marcia Martin, in memory of Eleanor Orkis
Theresa Mathiasmeier
Alice Matthews
Brain McCall
Lynora McDaniel, in memory of Howard "Rick" McDaniel
Eli and Joan** Medwar, in honor of Bettemarie Bond**
Michael Medwar
Josephine Minerva, in memory of Benjamin Pastore, via matching gift from Johnson and Johnson
Anne Morris
Tammy Morris, in honor of Maddie Morris
Edward Morrissey
Nancy and Brian Navis, in memory of Richard M. Harris
Louis Pacilio
Jennifer Patnode, in memory of Mary Patnode
Ellen Pierce and Chris Erickson, in memory of Jeff Dutton, Paula Southwick, Bob Sweet, and John Tucker
Lori and Richard Pike
Susan Plumer
Marjorie Quinn
Michelle Rosinek
David Rowland
Martha Sayles, in honor of Sally and Bill Bowers
Kathleen Saylor, in memory of Pat Brown, RN, MSN
Carol Schaffer, in memory of Mary Patnode
Erik Schten
Robert Shulman, in honor and in memory of Leo Kellerman, MD

yet have supported Oley by volunteering their time and talents. Note: when four gifts are given in honor of, or in memory of, an individual

Joan Shultz
Vi Schultz
Danny Sekelsky
Bob and Mary Smithers*, **
John Smithers, in honor of Bob and Mary Smithers*, **
Malini Srivastava, in honor of Mike Christenson
Josie Stone, RN, CPNP, CRNI
Mary Susan Thomas, RN, MSN
T. Bryan Tims
Cathy Tokarz, in honor of Bettemarie Bond** and family, Michael Medwar and family, and Todd and Susan Friedman
Jeffrey and Mary Jo Walch
Robin Weaver, in honor of the ThriveRx team
Robert Wente, "with thanks for all you do for those in need"
Phillis Wilcox, in honor of Philip Wilcox
Marion Winkler, PhD, RD, LDN, CNSC, in honor of Michael Medwar and his parents, and in memory of Dawn Smith
Pam** and Ally Winter
Lynn Wolfson**, MBA, EdS, in memory of Jody McCard's brother, Steve
Joe Woods, in memory of Colyn Woods
Natalie and Mary Wootten**, ***
Rosaline** and Bill Wu
Allan and Cheryl Yelner
The Yoo Family

Supporters (\$50-\$99)

Catherine Abrams, in honor of "those impacted by Hurricane Harvey"
Kathy Allen, in honor of Mandy Allen
Anonymous
Anonymous
Anonymous
Anonymous
Anonymous
Anonymous
Anonymous, in memory of Nancy Backinger
Anonymous, in memory of Imre Gombos
Anonymous, in memory of Carl Taylor
Peggy Aschenbeck
Blanca Barrios, "with thanks to Oley for supporting all the families and making a difference in our lives!"
Raymond D. Benge, Jr.
Barbara and Tim Blanchard
Jocelyn Block, in honor of Mel and Hadar Birger-Bray
Andrea Bolton
Diane Boone
Lynda Bosworth and Bonnie Resig, in memory of Lenore Gollop, "the strongest woman we know"

Lynda and Tom Bosworth, in memory of Evan Leibowitz
Sally Bowers
Eileen Bowes, in honor of Mike Medwar
Jonathan Brodtkin
Rebecca Busselman, "in honor of our super special brother-in-law, Michael Sherels!"
Molly Cromer
Bert Crosby
Christine and Arthur Dahl, in honor of Roslyn Dahl***
Marcia Denenholz's Mahjong group, in honor of Marcia**
Kathryn Devanny
James Edwards
James Ervin, in memory of Judith R. Ervin, RN
Gary and Pam Essary
Jessica Ferguson, in memory of Alisha Hoelle
Peggy Flavell
Janelle and Delbert Fortin, in memory of Jonathan D. Nelson
Iris Goldmacher, in memory of Howard K. Goldmacher
Helen Grimes, in honor of Jennifer Mason
Sophia Gutherz
Judith Hanson
Marta Harshbarger, in memory of Marjorie Harshbarger
Katherine Hatheway
Kimberly Holmes, "in honor of ThriveRx team, whose dedication and support is awesome!"
Mark Hopkins
Carol Ireton-Jones, PhD, RDN, LD, CNSC, FASPEN, FAND, in honor of Melinda Parker, MS, RD, CNSC
Elizabeth Kellerman
Karen Kellerman
Tina Kerrigan
Fred Levine
Robert Levy
Charles Lewis, in honor of Janet Lewis, pancreatic cancer survivor
The Longobardi family, in memory of Joseph Longobardi
Rachael, Jorge, and Ava Lopez
Janice Mah
Mahalchak family
Debra Marcus
Cesar Marroquin
Anita and Terry Martin
Tiffany Matthews, RDN
Jerry and Diane Mayer, in memory of Larry L. Mayer Jr.
Chris Michalski
Nadine Nakazawa, in honor of Joan Bishop***

Richard, Donna, Latayisha, Lazionte, and Kole Noble
Kathleen Novosel-Diedrich
William and Thelma Pierce, in honor of Dr. Ellen Pierce and Mr. Chris Ericksen's 20th wedding anniversary
Bren and Marilyn Price
Mary Probus, in memory of Lynda Yeabower
Linda Richman, in honor of Hadar and Melanie
Karen Rieck, in memory of Gary W. Rieck
Martha and Paul Robinson
William Sanders
Thomas Sanford
Jacqueline Schesnol, in honor of Jeffrey Schesnol
Maria and Zenaida Sciaino, in honor of Mary and Bob Smithers*, **
Dina Sevayega
Gail, Charles, and Chad Smithers's*, ** 50th wedding anniversary
Heather Springer
Ronna Staley, MD
Mark Thomas
Karen and Thomas Uhle, in honor of Paul Feyer
Ralph Valenti, in honor of Guiliana Valenti
Robert Warrington
Lois Wienshienk
Sheila Winfrey
Elizabeth Wittmann
James and Gloria Wittmann

Contributors (\$30-\$49)

Hannah Abeles
Anonymous
Anonymous
Anonymous
Anonymous, in honor of Gabe Eisenberg
Anonymous, in honor of Karen Hamilton and Sharon Lockwood
Anonymous, in memory of James Nagin, father of Lynn Wolfson**
Joan Barnett
Joan Bowling
Peggy Christ
Coleman family
Norma and Bruce Dayton
Carl and Jeanne Ferrentino
Theresa Freeman
Virginia and Guadalupe Garcia, in honor of Sean May's 18th birthday
Robert Goldberg
Penny Goldenhersh, in honor of Marcia Denenholz's** birthday
Joan Gordon
Mark Gouchie

Karen Hamilton, MS, RD, LD, CNSC
David Huebner, in memory of Marilyn Huebner
Maria Karimbakas, RD, CNSC
Donna Kloth, RN, CRNI, CNSC, "in honor of my son Rick who has Crohn's and the many consumers I work with at ThriveRx"
Pauline Kubizne
Christina Lampus, in honor of Hadar** and Mel Birger-Bray
Stacy Lee, in honor of Natalie Wootten
Lee Levknecht**
Sandra Lynn, in honor of Mike Sherels. "Sherels strong!"
Kayla Mahalchak
Elizabeth Mahoney
Margaret McDermott, "in honor of this wonderful and very necessary organization!"
Meredith Nelson
Christina Plante, in honor of Natalie Wootten
Peggy Roth
Laura Schellenberg
Karen and Michael Smollen, in honor of Lia Smollen
Valerie Sorensen
Allie Stickney, in honor of Sally and Bill Mary VanderKley
Bill and Amy Vohsing, in honor of Luke Vohsing
Sheri Wenzel, "in honor of the way Lynda Bosworth lives life!"

Friends (Up to \$30)

Theresa Adams, in honor of being on HPN for 34 years
Michael Aklufi
Melissa Alexander
Anonymous
Anonymous
Anonymous
Anonymous
Anonymous, in memory of Sheila Crusciel
Linda Arenburg
Madelena Bastian, in honor of Dwight Bastian
Michele Bateman, in honor of Kody Limbrunner, 13 years on G-tube nutrition
Jay and Carolyn Beck, in honor of Sally and Bill Bowers
Tom Behrendt and Lisa Kaston
Gary Bickerton
Cindy Anna Biercevicz, in memory of Anna Victoria Biercevicz

Donors, cont. pg. 8 ➡

Donors, from pg. 7

Fritzi Bodenheimer, in memory of James Nagin
 Leighanne Boone
 David Brown
 Abel Cabruja, through YourCause
 Deanna Clark, in honor of Rick Davis
 John Copp
 Judy Cosgrove
 George Crawshaw
 Wayne Damery
 Fredrick Davis
 Jean Demichelli, in memory of Josh Shapiro
 Leonard DiCarro
 Colleen Dixon
 Stephanie Eastman, via matching gift from Baxter International Foundation
 Peter Estabrooks
 Celia Fairbanks
 Georgie Field
 Sanford Flach
 Kelly Ford
 Ronald Gilroy
 Mae Godbee
 Ava Goldstein
 GoodShop
 Brenda Gray, PharmD, BCNSP, CNSC
 Kristi Griggs, in honor of ThriveRx Team
 Andrea Guidi***
 Colman Gulden
 Melanie Halliday
 David Harrison
 Mark Height, in honor of Mike Medwar
 David Higgins
 Jennifer Hisrich
 Trevor Humphrey
 Ronald and Noreen Iacobucci, in memory of Joyce Hydorn
 iGive
 Nicholas and Barbara Ioli, in honor of Joanne Platt**
 Helga Johnson
 Nora Johnson
 Tanya Jordan-Jackson
 Frank Kaufmann, Jr.
 Lauren Kaufman

Allison Kinney
 William Langford
 Mary Jane LaPorta, in memory of Norma Poland
 Julie Lipkin
 Paulette Mabardy
 Michelle Margeson
 Ray McIssac
 Sue McKallor
 Julia Owens, in memory of Michael Owens
 Tammy Ozoskey
 Jim, Sarah, Abigail, and Gus Palya
 Helen Pizzuti
 Terry Quinn
 Michael and Lauren Raffe, in honor of Aidan Raffe, 12 years on HPN
 Sarah Rausch
 Becky Richardson
 Anthony Robichaud
 Eleanor Roppel
 Thomas Rush, in honor of the Oley Foundation, "a continuous holiday to people everywhere"
 Joan Salkeld, in memory of Don Norton
 Ed Sargent
 Ann Savattieri
 Lauren Schrero
 Alan Segal, in memory of Robin "Peaches the Clown" Lang
 Kevin and Amy Shearow, in honor of Dr. and Mrs. Breaux
 Linda Sierocuk
 Joanne and Jim Skinner
 Kenneth Skinner
 Sam Skinner
 Philip Sortino, in memory of Donna Sortino
 Lisa Spaddy
 Kitty Staskelunas
 Diane Talbot
 Jean and Asa Talbot
 Enrica Thure, in memory of Greg Tongol
 May To, RD
 John Trzaskos
 Carol Walsh, in honor of Mary Ellen Costa

Michael Wenz
 Carolyn Wijnholds
 Greg Wilson
 William Winnewisser
 Fiona Winterton
 Yudan Xu, through YourCause
 Donna Yadrich, MPA, CCRP
 Judy Tin Tung Yeung, through YourCause
 Larry Zbanek, "new to life with a feeding tube and so happy to find the Oley website"

In Memory of Ann Hill DeBarbieri

Anonymous
 Anonymous
 Jean D. Brown
 Paul DeBarbieri
 Carl and Jeanne Ferrentino
 Pauline Kubizne

In Memory of Cecil Ronald Rayworth

Amherst Jr. A Ramblers 97
 Linda Arenburg
 Gary Bickerton
 David Brown
 John Copp
 George Crawshaw
 Wayne Damery
 Fredrick Davis
 Peter Estabrooks
 Georgie Field
 Ronald Gilroy
 Mark Gouchie
 David Harrison
 David Higgins
 Mark Hopkins
 Allison Kinney
 Joan Lavers
 Janice Mah
 Ray McIssac
 Anthony Robichaud
 Eleanor Roppel
 Joanne and Jim Skinner
 Kenneth Skinner
 Sam Skinner
 Greg Wilson

In Memory of Don Young

Anonymous
 Anonymous
 Jerry and Doty Fickle
 Gail Egan, MS, ANP, "Don's humor, kindness and insight served as a guide for both consumers and clinicians"
 Laura Ellis, PhD, RD
 Beverly Engle
 Joseph Goyette
 Lenore Heaphey and John Worthley
 Rose** and Jeff Hoelle

Thomas and Christine Lally
 Anita and Terry Martin
 Eli and Joan** Medwar
 Michael Medwar
 Kathleen Novosel-Diedrich
 Melinda Parker, MS, RD, CNSC, "Don enriched all of our lives"
 Lori and Richard Pike
 Rosaline** and Bill Wu

In Honor of Lyn Howard, MB, FRCP*

Sharon Alger-Mayer, MD
 Carl and Jeanne Ferrentino
 Ron and Lisa*** Metzger
 Erik Schten, "a giant in her field and a wonderful human being! Keep up the great work Oley!"

In Honor of Phil Kellerman***

Harry and Ruth Ann Forgan
 John D. Hutchinson and Dr. Kathy Platoni
 Janet and Frank Ivory-May
 Karen Kellerman
 Fred Levine
 Martha and Paul Robinson
 Karen and Thomas Uhle

In Honor of Swapna Kakani**

Andrea Bolton
 Bhavani Kakani
 Michael Medwar
 Soleo Health

In Honor of John Mahalchak**

Anonymous
 Lauren Kaufman
 Kayla Mahalchak
 Michelle Margeson
 Kitty Staskelunas

Matching Gifts

Baxter International Foundation
 FM Global Foundation
 The GE Foundation
 Johnson and Johnson

Fund-raisers

Amazon Smile
 Axela Care/BriovaRx Infusion, booth activity at Oley conference
 GoodShop
 iGive
 Bharath Surapaneni's Chicago Marathon run, in honor of Swapna Kakani**
 Network for Good
 Edithe Swensen charity class at Rocksport Indoor Climbing Gym

*Oley Trustee

**Oley Ambassador

***Oley Staff

A Special Shout Out

Thank you to the following companies for their **in-kind gifts** in 2017: Alcor Scientific; Dorsey and Whitney, LLP; Google AdWords; Magic Wig Productions; and Zone 5.

Thank you to those who helped us **settle into our new offices**: Kim, Greg, and Nicholas Butler; Joe Harrington; Barbara Kapuscinska; Peter Kelly; and Jim Senese. And thanks to all of our members for your patience with us during this time.

Come visit us in our new digs!

Updates on IV Fluids Shortages

To say the shortages of IV fluids is a multifaceted problem is an understatement. To understand it on even a basic level (which is what we're hoping to present here), you need to know: the terms "large volume parenterals" and "small volume parenterals" (LVP and SVP for short); that part of any given shortage could be a problem with the bags or containers that hold the LVPs and SVPs, in addition to shortages of the various things that go into those bags; and that a shortage of SVPs has an impact on the supply of LVPs, as health care providers may substitute LVPs for SVPs if SVPs are in short supply.

LVP saline bags are typically used to hydrate patients and SVP saline bags (generally in 50 and 100 ml sizes) are often used to deliver other IV medicines. FDA and manufacturers had taken steps to address a shortage of LVPs before Hurricane Maria hit. FDA had approved Baxter's importation of LVPs from its manufacturing facility in Mexico, for example. Hurricane Maria, however, affected the production of SVPs, which has put added pressure on the supply of LVPs.

To understand what has been done to address the shortages and where things stand now, we looked to the FDA, and to Baxter, whose manufacturing facilities in Puerto Rico were affected by Hurricane Maria this past fall.

FDA Responses

From January 16 and February 1, 2018, FDA press releases

The FDA has:

- Worked with manufacturers to ensure that their Puerto Rico facilities can operate at full capacity.
- Worked with manufacturers such as Baxter and B. Braun to import product into the U.S. from their foreign facilities.
- Approved importation of IV saline products from additional companies, specifically Fresenius Kabi and Laboratorios Grifols.
- Extended the expiration dates of certain products, including some 500 ml saline bags (after examining company data to ensure it meets FDA quality and safety standards).
- Continued to identify supply gaps and work with manufacturers who may be able to fill these gaps.

Baxter's Global Response to Hurricane Maria

William Rader, Global Director, Corporate Communications, Baxter International Inc.

Hurricane Maria hit Puerto Rico with devastating effects on September 20, 2017, and complex recovery efforts continue across the island. Baxter activated a global response to Hurricane Maria—to support the needs of patients and healthcare providers in the U.S. and to support our employees on the island—and we continue to make progress on the road to a full recovery of our operations.

All of Baxter's manufacturing facilities are now connected to the electric grid and are operating at pre-hurricane levels. Reliable and stable electric power is key to our ongoing efforts to restore sustainable manufacturing operations. Baxter has maintained backup diesel generators in all of our Puerto Rico facilities in case of power interruptions, which still occur intermittently.

Addressing Current Product Supply Demands

In Puerto Rico, Baxter manufactures MINI-BAG and MINI-BAG Plus (small volume parenterals, or SVPs) Container Systems, which are primarily used in the pharmacy to compound or admix a medication or to aid in the delivery of a medication, as well as amino acids and certain pre-mixed products. Restoring reliable supply of these products remains our priority.

To help support product supply for the U.S. market, Baxter activated targeted recovery strategies across our global manufacturing network, including working with the FDA to secure regulatory discretion for the temporary special importation of certain products (including nutrition products) from Baxter facilities in Ireland, Australia, Canada, Mexico, England, Italy, and Brazil. Millions of new units of special importation products have been shipped to hundreds of U.S. hospitals since late October and product continues to enter the supply pipeline. We also continue to work with the FDA to explore opportunities to leverage additional Baxter manufacturing facilities to help address product demand in the U.S.

Overall, progress is being made on product supply thanks to the improving production in Puerto Rico and the special importation products. To that end, we expect to return to more normal supply levels for products made in Puerto Rico in the coming weeks.

Supporting Baxter Employees and Communities

Baxter mobilized quickly in the aftermath of the storm to get our facilities back on line, and to help our local employees and their communities. Baxter's local work force not only faced daily challenges getting to and from work as transportation and services were damaged or destroyed, but all of our 2,000 Puerto Rico team members had to deal with the urgent basic needs of their own families and neighbors. Baxter provided a combination of product donations, financial assistance, and on-the-ground support to our employees in Puerto Rico to help maintain patient access to our life-sustaining products and therapies.



Mallory Cyr addressing clinicians as part of a panel at the ASPEN annual meeting held this January in Las Vegas, Nevada. Mallory is a long-time Oley member and HPN consumer, which positioned her well to discuss the issues of transitioning from pediatric to adult health care. The Oley booth received many visitors and Oley staff is eager to share with you all they learned at the excellent educational sessions.

Gastroparesis, from pg. 2

supported proposals on Medicare coverage, some of which have been enacted (though not enough). FDA has been very helpful in defining what should be measured and reported in trials for Gp.

Diagnosing Gp

The GpCRC looked at people who have the symptoms of Gp with, and without, delayed gastric emptying. We found that people with what we call gastroparesis-like syndrome (GLS) who have non-delayed gastric emptying are identical in every way to those with Gp except for emptying. I mean in every way—age, sex, underlying illness, if known, etc. So gastric emptying studies may not be the best way to differentiate patients to make a diagnosis of gastroparesis.

When placing a j-tube or gastric stimulator, we often have the opportunity to do full-thickness gastric biopsies. The GpCRC has set up a core laboratory to examine these biopsies, looking at things like the interstitial cells of Cajal (ICC), which are decreased in almost all patients with symptoms of Gp. As those numbers get lower, the gastric emptying becomes more delayed.

In figure 2, the circular muscle is on the upright axis (the Y axis). This is the number of ICC per high power field (a common standard of magnification). On the right are the healthy control patients. They have about five or six ICC per high power field. The Gp patients (on the left) have less than two or three per high power field and have delayed emptying. The patients in the middle have chronic unexplained nausea and vomiting (CUNV). They have a decreased number of ICC, but not enough decrease in ICC to be delayed.

A lot of patients are non-delayed in their emptying study. A doctor might say to these patients, “You can’t really be sick, because you don’t have Gp. You’re not delayed.” To me, that’s a little bit like saying to a patient with heart disease and angina, “Come back and see me when you have your heart attack. Then I’ll know you are really sick and I’ll take care of you.”

Of course that would be crazy. No one would intend to treat patients that way. But patients with nausea and vomiting are treated that way at times. So in my opinion, this is really a spectrum. There is decrease in ICC for a number of reasons that are not fully understood; when finally the ICC get low enough, there is delayed emptying.

While in my and others’ view, Gp and GLS can be viewed as part of a spectrum, many others would not agree with us. Many people in Europe would not agree with us for example, so there is no general agreement or consensus.

A couple of years ago, the Diabetes Complications Consortium, also NIH-funded and related to the GpCRC, funded our center to look at a small group of diabetic and nondiabetic patients with the symptoms of Gp. This resulted in new work that has not been widely circulated. We found that these patients were systemically inflamed and had ab-

normal autonomic nervous system measures. We then looked at their enteric (gastrointestinal) nervous system by full thickness biopsies, as well as other biopsies, and found they were abnormal as well.

We also looked at electrophysiology, which is what I’ve worked on for decades, and found these patients had abnormal activity. (Just like with the heart, you can have electric abnormalities in the stomach.) We also found hormonal abnormality; even if not diabetic, many patients with Gp have abnormal metabolic and appetite hormones.

My conclusion is that Gp can be looked at as a systemic disease with variable presentations of symptoms. The work is not yet published, but the investigation is registered on clinicaltrials.gov for anyone who is interested.

In this study, we also looked for the effects of gastric electrical stimulation (GES), and showed several possible mechanisms of action related to pathophysiology. I could talk much more about GES now, but won’t do so, due to limited space. So I’d like to switch to a discussion of therapies. I’ll use the abbreviation COPS: C for chronic disease, O for options for therapy, P for particulars, and S for electronic searches.

COPS

Chronic illness care, the first of what I call the “Cs,” starts with home care and primary care. Then there’s internet care, which I think almost everybody uses next these days, as well as acute care, chronic care, and hospital care. Many patients have experienced all of these, but they need to be integrated, in my opinion, for optimal patient care.

Team work, with ongoing communication, is essential. It’s gotten a little easier with texting and pagers, but it is amazing to me, as a former primary care doctor, how many people are

seen and taken care of by others without all team members being informed. Unfortunately, electronic medical records haven’t solved this problem—or not yet anyway.

I’m going to spend more time on “O,” the options for therapy, because that’s the primary focus of this article. I will subdivide the “Os” into the “Ds”: diet and nutritional support; drugs; devices; disrupt/divert; and detoxify. I’ll discuss each one separately.

Why are there not more treatments? One of the many reasons is that there is still the belief that Gp is not a real disease, that it is not a biologic problem. But beliefs are about religion, and science should be about data. In addition, there is a lack of understanding of mechanisms. As we discussed, the GpCRC and many others are starting to understand the mechanisms of Gp much better.

There are limited resources for new drugs, though that, too, is changing. And there is often a narrow view about the range of therapeutic options available for patients. All of these contribute to the current lack of good treatment options for Gp. Let me spend time on the “Ds” in more detail.

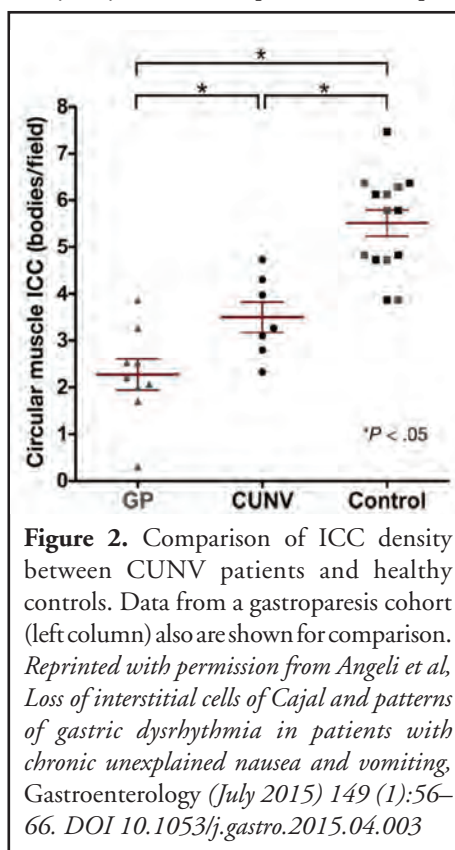


Figure 2. Comparison of ICC density between CUNV patients and healthy controls. Data from a gastroparesis cohort (left column) also are shown for comparison. Reprinted with permission from Angeli et al, *Loss of interstitial cells of Cajal and patterns of gastric dysrhythmia in patients with chronic unexplained nausea and vomiting*, *Gastroenterology* (July 2015) 149 (1):56–66. DOI 10.1053/j.gastro.2015.04.003

Diet and Nutritional Support

The traditional approach is to advise frequent small meals of limited digestibility. However, this only works for certain patients. Also, the majority of people with Gp—you won't be shocked by this, but I think many were—are never seen by a nutritionist, even in referral centers. Part of the reason for this is we don't work with nutrition colleagues enough, part of it is reimbursement, and part of it is we (providers) don't think of it.

Eating by mouth is the best option, but not everyone can do this. Small bowel (jejunal) feedings, as with a j-tube, are the next best option. We usually try an endoscopic nasojejun (NJ) tube before placing a more long-term j-tube. But there is limited expertise with feeding tubes, and not everyone can have successful small bowel feedings. Some patients don't have a complete and functioning small bowel so it doesn't work. My own concern is that most people who get tubes never had a small bowel (or gastric) full-thickness biopsy. To me that's kind of like treating cancer and never having a tissue diagnosis. You don't know what's there, what the nerve and muscle abnormality is, so it is really going to be hard to treat it appropriately.

For many patients, parenteral nutrition (PN) is the only option. A full discussion of home PN (HPN) is beyond the scope of this article. For now, I'll say that it is wonderful to have this option, but HPN is not easy, inexpensive, or risk-free. And, unfortunately, expertise in HPN varies widely, although there are many excellent HPN pharmacies. Support groups like the Oley Foundation are crucial for people on HPN.

Drugs

Drugs can be discussed by class: antiemetics, prokinetics, and others (see table 1). Not all of these drugs are available in the U.S., and some are investigational. Fortunately, there is renewed interest by pharmaceutical companies in drugs for Gp.

Antiemetic drugs are helpful. Unfortunately, a nationwide shortage of promethazine (Phenergan®) has been ongoing; a lot of our patients at home can't get it at times. Aprepitant, which addresses the symptoms of Gp, has documented efficacy, but is quite expensive.

Table 1. Antiemetic and prokinetic medications used with Gp syndromes

Class	Generic Name	Brand Name
Antiemetic	aprepitant diphenhydramine dronabinol ondansetron other drugs related to ondansetron prochlorperazine promethazine scopolamine	Emend® Benadryl® Marinol® Zofran® Compazine® Phenergan® Transderm Scop®
	domperidone erythromycin metoclopramide	Motilium (several) Reglan®

We have only one approved drug for Gp in the U.S.: metoclopramide (Reglan®). It is a prokinetic but has a number of safety issues, both short- and long-term, and so it is recommended for a maximum of about six to eight weeks. Erythromycin can be also helpful, but it may not work long-term and some people can't tolerate it. Other drugs have not been studied systematically.

There are also investigational drugs not approved in the U.S., like domperidone. It is safer than metoclopramide, but complex to obtain. Other investigational drugs are in clinical trials, all under FDA guidelines. The FDA, as always, is trying to respond to patients and patient groups with new ways to get drugs more quickly.

Most of these are oral drugs. Most are small tablets. Some are available as capsules, suppositories, or liquids. Some can be given intravenously. IV therapies are, again, beyond the scope of this talk. There are real risks with IV therapies, including IV access issues, blood clots, bleeding, and infections, some of which can be life-threatening, but there are benefits as well. There are some coverage issues by insurers for IV therapies, and you need a dedicated team to administer.

Drugs for Pain in Gp

This is a very complex issue. It is difficult for most patients and most providers, and the discussion is beyond the scope of this paper. We try to get every patient with Gp with pain to see a pain specialist, with the idea that pain should be able to be treated—even though we realize that doesn't often happen in practice. A separate communication about this important topic is needed and will hopefully follow by experts in the field, as there exist other ways to treat pain, such as neuromodulation. [Editor's note: We are working on a follow-up article on this topic.]

Devices for Gp

Devices for Gp are of limited availability. Medtronic's Enterra™ neurostimulator is the only FDA-approved device. There are many regulatory, insurance, and other issues with neurostimulators. This is primarily what I have worked on for the past twenty-five years. The first current neurostimulator was implanted in 1992. It was approved by the FDA in 2000 as a Humanitarian Use Device, which has some limitations on use. GES was recommended for compassionate use by the American College of Gastroenterology Gp guidelines in 2013. This neuromodulation therapy can be very helpful, but it is beyond the scope of this article.

Diverting and Disrupting

What do I mean by this? The stomach has an inlet, upper and lower parts, and an outlet. There is increased interest in the lower, pyloric outlet function. This lower outlet dysfunction is clearly an issue for many patients, especially those with delayed emptying. There are many new approaches, including endoscopic approaches, but all attempt to divert/disrupt the pyloric sphincter. None of these have been shown conclusively to consistently help, but I try to discuss them with patients and say we can try to do something about your pylorus. This is something the GpCRC and others are actively looking at.

Detoxify

Many patients have systemic issues, generalized symptoms, and disordered physiology. But some have neuromuscular issues, as

Gastroparesis, cont. pg. 12 ➤

Gastroparesis, from pg. 11

measured by blood and/or tissue, which we think is in part due to systemic inflammation. Therapies like IV immunoglobulin (IVIG) act on the immune system, and although this is an off-label use for IVIG, can be quite helpful for some patients. There are three peer-reviewed published studies, many case reports, and other articles in the works. It is something to at least be aware of.

Particulars

The “Ps” include the patient and protectors (by which I mean the family), providers, partnerships, pharmacies, and professional companies and insurance companies—working together. We really need a true team, with any chronic illness; it is crucial. I don’t think I need to explain to this audience how important this is. Without it, we just can’t deliver good care.

Searches

This could have been called “COPES,” for electronic searches, but I don’t mean Internet searches. I mean what I call, first, “PreSearch,” which is talking about the issues important to patients. Then there is “ReSearch,” which is formal work like that done by GpCRC and others. “ProSearch” is the education of providers. I knew nothing about Gp after my first residency, and I was well educated in primary care, both internal medicine and family medicine. “FuSearch” is how we can get to the future. As part of this, support groups are crucial, and federal resources—NIH, FDA, Medicare, and others—are very important. It all boils down to education, teams, funding, and working together.

Summary

Most things in medicine are opinions, not facts. I have given you my opinions. As I see it, over the past fifty years we’ve gone from bad, to better, and to now good in many areas. The future, I hope, will be better yet.

I have tried to focus on therapies, but also tried to offer background—why things are the way they are right now—and a bit about the physiology

of the GI tract. Several important areas, such as medications and other treatments for pain associated with gastroparesis, are not discussed here.

Teams and support groups, in the context of the illness we call Gp, which, when severe, is GI tract failure, are the key in my opinion. A number of our patients end up getting PN or small bowel transplants. If you have severe Gp, you have GI tract failure.

My Bottom Lines

Gp has been misunderstood, which is not unusual in the history of medicine. It takes decades (or longer) to understand many illnesses. Gp is generally now accepted as a “legitimate” illness, although still not everyone agrees. The U.S. NIH and FDA are engaged in work on this problem. Medicare (i.e., as part of the government) can be lobbied, by patients, and their family, friends, and representatives. Institutions don’t always listen to me as a physician, but patients are voters.

Much has been learned, especially over the last decade, about Gp and gut failure, but much more work needs to be done. Partnerships of patients, protectors, and providers may be the key to making this happen. Web access is very important. The GpCRC website and others, support groups like Oley, IFFGD, G-PACT, AMGD, and others, are all important. ¶

Oley Supply Program Updates

The Oley supply program has been a huge success over the last few decades, and we are always looking for ways to make it even better.

There is a new call-in number to request or donate supplies—(267) 580-5155—and we are now requesting everyone to join Oley prior to utilizing our program. This will allow us to better serve our members with updates, events, and timely information.

We would like to thank our volunteers, Bettemarie Bond and Robin Bodnar, who keep this program going. We certainly could not do this without their dedicated efforts and generous contribution of time.

Join us in congratulating our nutrition team for winning the ASPEN Clinical Nutrition Team of Distinction Award



Awarded by the American Society for Parenteral and Enteral Nutrition in recognition of ThriveRx for excellence in interdisciplinary clinical nutrition.

“ThriveRx delivers high-quality, patient-centered, and compassionate care. I give them 10 out of five stars.”
—Shawna, ThriveRx Consumer

888.684.7483 | info@thriverrx.net | thriverrx.diplomat.is

Copyright © 2018 by Diplomat Pharmacy Inc. Diplomat, Diplomat Specialty Infusion Group, and ThriveRx are either trademarks or registered trademarks of Diplomat Pharmacy Inc. All rights reserved. DSIG-164536-1802

Being Me, from pg. 1

not correlate well. But it turned out to be one of the best decisions we have made. I could be me. I could walk around and not have to be so focused on whether any of my “problems” would occur. I did not have to act different to fit in. I walked around in my pajamas, my mask and my gloves, not feeling like I stuck out. I didn’t have to be self-conscious that one of my tubes may peek out. And I spent less time worrying about whether or not I was being stared at or if one of my tubes leaked or whether that smell was coming from me. Being me and leaving my insecurities on the back burner allowed me the time and confidence to make connections and get the most out of the conference.

We saw people with IV fluids hanging on hangers and people with backpacks with lines showing. There were people of all ages and from all over the United States, and even abroad. For some, like us, it was the first conference and others had been to multiple Oley events.

Because we did not find out about Oley until a short time before the conference, we were not able to stay at the hotel where the conference was taking place. There were a lot of times when we wished we could jump on an elevator, go to our room to deal with a problem, and come right back. That was not possible, but we made it work.

Once we checked in to the conference, we collected our name tags, t-shirts, and bags. Everyone could put color-coded stickers on their name tags. Each one stood for something, like care taker or loved one, HEN or HPN patient, and so on. It was good, because you could see the sticker and know upon approaching where they fit into the dynamic. At check-in we got the itinerary. I was exhausted, so we decided to skip the welcome event. I’m pretty sure we went back to the hotel and passed out. When we saw the event posted on the Oley website this year [2015], we knew we should act promptly. I am happy that we do have a room at the hotel where the conference will be [in 2015], and we cannot wait.

Everybody learns in different ways, and that is one of the reasons I found this conference to be successful. In the mornings they had a little continental breakfast outside the conference room and then everybody came together for the “main session.” There was one each morning for two days, and each had multiple speakers. I have a hard time focusing, and sitting in the same spot for a long time causes a great deal of pain. However, I know that seminar-like learning is the best way of learning for others. After the main session there was a break, during which lunch was served and the exhibit hall was open.

In the afternoon, you had a choice of which “breakout sessions” you wanted to attend. Some of the topics were caring for your tubes, nutrition, clinical trials, swimming and bathing with catheters, and dating. The groups were much smaller than the morning sessions and very interactive. I found out that other people had a lot of the same questions I had. For example, I wear pajama pants most of the time. Due to my venting G-tube, I cannot wear pants that hug close to my skin. I also tend to wear tops that are dark and baggy, self-conscious my tube will show. In one of the sessions we went to, they touched on that topic, and a lot of people had the same concern. In this specific

group, there were a lot of people that have been sick a lot longer than me. They have had more time for trial and error.

For this trip, I had packed my normal apparel of pajama pants, but I had also packed a wildcard—a purple skirt, just in case. That evening we were attending a special dinner, and I wore the purple skirt and was glad I did. When we went home, I resorted back to pajamas but I started to include some long, loose-fitting skirts and dresses. Last year I even wore a bathing suit. On our trip this year, my suitcase will include a good balance of sleepwear and classier wear.

Also going on at the conference during lunch time and early afternoon was something similar to a job or college fair, with vendors from different companies. We got a really nice bag and by the end of the conference it was full of brochures, samples, and fun memories. Companies made sure they got to engage with you.

There were people from different home care agencies, others that had new products for HEN and HPN, and even the TSA was there, giving tips on how to get through security check points. Exhibitors caught your attention by having something fun to do or giving away little things. At my home care company booth, you got to use props to look like a pirate and have pictures taken in front of a cardboard pirate ship. We actually framed them and

still have them. There also was a man making really good caricatures. I recently came across ours, and it still makes me laugh.

The evenings were a time for meet and greets and exchanging stories. One of the nights was a cookout. We were sitting alone and a family—a mom, dad, grandma, and two kids—joined us. Making connections like that is the best part.

Another evening was the silent auction. There was everything from handmade jewelry to gift baskets, and there were raffles. I bid on a large stuffed dog. At first it was a joke, but we ended up winning him. At the end of the auction, a little boy suggested I name the dog Hugo. So I did. The auction raised money for the Oley Foundation, so it was for a good cause. Javi and I are already talking about this year’s auction and what our budget is.

Checkout day they held a brunch. We sat at an empty table and Javi went to get food. By the time he came back the table was full. A woman from Israel sat by us. She had come by herself because of the cost and because her child cannot travel well because of illness. She came to see what products might be available. She said companies will not deliver to Israel.

I now know that people want to be approached and want to make connections. I never like to tell my story because I don’t like when people say, “Oh, I’m so sorry” and feel emotional for me. But I am hoping I will make more connections this year.

I wanted to include briefly some very inspiring statistics of the big picture: This Oley conference welcomed over 500 people to Cape Cod, including 87 children, and 150 of the total were new attendees. There were people from Massachusetts to California, to Ireland, England, and Israel. There were close to forty exhibitors showing and teaching about new products and services. And the silent auction raised over four grand. ¶

Being me...allowed me
the time and confidence
to make connections and
get the most out of the
conference.

Conference, from pg. 1

we will consider applications from those who have attended an Oley conference in the past, as well. Be sure to submit your paragraphs to get on our waiting list. Details at www.oley.org/supportforconfravel or contact Cathy at harrinc@amc.edu.

- **Topics to be covered at the meeting** include, but are not limited to: living well while dependent on nutrition support, managing intestinal failure, transitioning to independence, avoiding complications, the role of the dietitian, insurance reimbursement, blenderized tube feeding, skin and wound care, vascular access, advance directives, lab reports, and self-care for consumers and caregivers.

- **Kidz Club** is designed to provide supervised entertainment for kids while parents attend educational sessions. Age-appropriate activities will be offered in the Playschool room (infants to 8 years old), and Tween Room (9 to 14 years old). Morning and afternoon sessions will be provided.

Tweens are welcome to “hang out” and enjoy video games and chatting with their peers in the Tween Room. Limited supervision will be provided. In the Tween breakout session, youth will come together with a moderator to discuss issues of importance to them, centering on things connected to HPEN.

Note that we cannot provide medical care; hook up, disconnect, or troubleshoot infusions or tube feeding; change ostomy bags; administer medications; and so on.

- **Jammin’ Jammies** is a chaperoned evening activity for children ages 7+. A choice of G or PG movie will be shown, and kids can create funny memories with friends in our photo booth! Parents are welcome to join in the fun.

- **Silent Auction** items are needed. Let’s make this event the best ever! Bring your contributions with you or email marywootten.oley@gmail.com to make arrangements to ship.

- **Annual Walkathon** registration sheets are posted at www.oley.org/AnnualConference. T-shirts will be provided to all walkers with a suggested minimum donation of \$20. Start getting pledges today! Funds raised help support all Oley programs and are tax-deductible. The route is short (but can be extended to accommodate any energy level). The passion amongst us is always apparent, and the display of “living” on HPEN unmatched.

- **Breakfast and Brainstorming** will be our closing session. Following immediately after the Walkathon, it will be filled with expertise, experience, opportunities to ask questions—and breakfast! Interact with some of the premier clinicians in the field of home nutrition support and experienced consumers... all eager to help you with information, support, and hope. We expect this to be an extremely interactive session with a great exchange of information. Bring your questions! Updates will be posted at www.oley.org as the experts are confirmed. At the conclusion of this special event, we’ll capture photos, share on social media, and bid our farewells.

- Go to www.oley.org/AnnualConference to register and learn more. See you in Memphis!



Notable Individual Gifts

Among the individual contributions we receive, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. We are grateful for the following gifts received from November 25, 2017, to February 16, 2018.

Tributes

In honor of Mandy Allen; Rebecca Appel and Daniel Appel, and with great appreciation to Oley; Nancy Backinger; Dwight Bastian; Bettemarie Bond and family; Lynda Bosworth, “and the way you live life”; Sally and Bill Bowers; Dr. and Mrs. Breaux; Mike Christenson; Mary Ellen Costa; Roslyn Dahl; Rick Davis; the recovery of Marcia Denenholz; Jackson Dietel; Clifton Dodge; Todd and Susan Friedman; the recovery of Natalie Ginsburg; Dr. Lyn Howard, “a giant in her field and a wonderful human being” and “a very wonderful doctor”; Phil Kellerman, “a most generous and empathetic man”; Barbara Klingler; Aidan Koncius; Kody Limbrunner, thirteen years on G-tube nutrition; Janet Lewis, pancreatic cancer survivor; John Mahalchak; Jennifer Mason; Jerry Mayer’s birthday; Ruby “Kick Ass” McDonald, “as we celebrate her first birthday”; Michael Medwar and family; Leslie Noyes; Melinda Parker, MS, RD, CNSC; Dr. Ellen Pierce and Mr. Chis Ericksen’s twenty-first wedding anniversary; Aidan Raffé, twelve years on HPN; Jeffrey Schesno; the Erik Schten family; Mike Sherels, “Sherels strong!”; Tanner Shuman; Bob and Mary Smithers’ fiftieth wedding anniversary; Lia Smollen; Guiliana Valenti; Luke Vohsing; and Philip Wilcox

Memorials

In memory of Ann DeBarbieri; Anna Victoria Biercevicz; Patricia Brown, RN, MSN; Sheila Crusciel; Jeff Dutton; Charlie Eidem; Judith Ervin, RN; Howard K. Goldmacher; Imre Gombos; Bruce Groeber; Richard M. Harris; Marjorie Harshbarger; Alisha Hoelle; Marilyn Huebner; Joyce Hydorn; Larry Karacki; Shirley, Arnold, and Fred Klein; Robin “Peaches the Clown” Lang; Larry L. Mayer Jr.; Howard “Rick” McDaniel; Jonathan D. Nelson; Clarence “Oley” Oldenburg; Eleanor Orkis; Michael Owens; Mary Patnode; Norma Poland; Gary W. Rieck; Bob Rubin; Todd Schwartz; Donna Sortino; Paula Southwick; Bob Sweet; Carl Taylor; Greg Tongol; John Tucker; Lynda Yeabower; and Don Young

Fund-raisers

Amazon Smile; Facebook; Goodshop; Google search; Network for Good

Thank you for all gifts and the kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration.

2017 Corporate and Foundation Program Support

Abbott Laboratories
Applied Medical Technology, Inc
AxelaCare
Baxter
B. Braun Medical Inc.
Coram CVS/specialty infusion services
Covalon Technologies Ltd.
Fresenius Kabi, USA
Halyard Health
Kate Farms
Medtronic
Nestlé Health Science
Nutrishare, Inc.
Option Care
Daniel F. and Ada L. Rice Foundation
SBS Cure Project
Shire
ThriveRx, Inc.

Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. Learn how you can make a difference by calling (518) 262-5079 or visiting www.oley.org/plannedgifts.

<i>Felice Austin</i>	<i>The Groeber Family</i>	<i>Rodney Okamoto, RPh,</i>
<i>Jane Balint, MD</i>	<i>Valerie Gyurko, RN</i>	<i>& Paula Okamoto</i>
<i>John Balint, MD</i>	<i>Alfred Haas</i>	<i>Kay Oldenburg</i>
<i>Joan Bishop</i>	<i>Shirley Heller</i>	<i>Harold & Rose Orland</i>
<i>Ginger Bolinger</i>	<i>Alicia Hoelle</i>	<i>Judy Peterson, MS, RN</i>
<i>Pat Brown, RN, CNSN</i>	<i>Jeff & Rose Hoelle</i>	<i>Clemens Pietzner</i>
<i>Faye Clements, RN, BS</i>	<i>Lyn Howard, MD</i>	<i>Beverly Promisel</i>
<i>Katherine Cotter</i>	<i>William Hoyt</i>	<i>Abraham Rich</i>
<i>Jim Cowan</i>	<i>Portia & Wallace Hutton</i>	<i>Wendy Rivner</i>
<i>Rick Davis</i>	<i>Kishore Iyer, MD</i>	<i>Roslyn & Eric Scheib Dahl</i>
<i>Ann & Paul DeBarbieri</i>	<i>Doris R. Johnson</i>	<i>Susan & Jeffrey Schesno</i>
<i>David & Sheila DeKold</i>	<i>Darlene Kelly, MD, PhD</i>	<i>Doug Seidner, MD, FACP, CNSP</i>
<i>Dale & Martha Delano</i>	<i>Family of Shirley Klein</i>	<i>Judi Smith</i>
<i>Tom Diamantidis, PharmD</i>	<i>Jim Lacy, RN, BSN, CRNI</i>	<i>Steve Swensen</i>
<i>Gail Egan, MS, ANP</i>	<i>Robin Lang</i>	<i>Cheryl Thompson, PhD, RD, CNSC,</i>
<i>Selma Ehrenpreis</i>	<i>Hubert Maiden</i>	<i>& Gregory A. Thompson, MD, MSc</i>
<i>Herb & Joy Emich</i>	<i>Laura Matarese, PhD, RD,</i>	<i>Cathy Tokarz</i>
<i>Jerry Fickle</i>	<i>LDN, CNSC, FADA, FASPEN</i>	<i>Eleanor & Walter Wilson</i>
<i>Don Freeman</i>	<i>Kathleen McInnes</i>	<i>Marion & Larry Winkler</i>
<i>Linda Gold</i>	<i>Michael Medwar</i>	<i>James Wittmann</i>
<i>Linda Gravenstein</i>	<i>Meredith Nelson</i>	<i>Patty & Darrell Woods</i>
<i>Deborah Groeber</i>	<i>Nancy Nicholson</i>	<i>Rosaline Ann & William Wu</i>

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their strong commitment.

PLATINUM LEVEL PARTNER (\$70,000+)

Shire

GOLD MEDALLION PARTNER (\$50,000–\$69,999)

ThriveRx, Inc.

SILVER CIRCLE PARTNERS (\$30,000–\$49,999)

Coram CVS/specialty infusion services
Nutrishare, Inc.

BRONZE STAR PARTNERS (\$20,000–\$29,999)

Baxter International Inc.
Cardinal Health
Fresenius Kabi USA
Halyard Health, Inc.
Option Care

BENEFACTOR LEVEL PARTNERS (\$10,000–\$19,999)

BioScrip, Inc.
Nestlé Health Science
Real Food Blends

PATRON LEVEL PARTNERS (\$5,000–\$9,999)

Applied Medical Technology, Inc.
Apria Healthcare
AxelaCare/BriovaRx Infusion
Cook Medical
Functional Formularies
Soleo Health

Learn more at www.oley.org/IndustryLandingPage

LifelineLetter

The Oley Foundation

Albany Medical Center, MC-28
99 Delaware Avenue
Delmar, NY 12054

NON-PROFIT ORG.
U.S. POSTAGE
PAID
PERMIT NO. 687
ALBANY, N.Y.



Are You Missing Out?

If Oley doesn't have your email address, you're missing conference news, event invitations, HPEN FDA Alerts, and other timely updates.

Fix this today: email harrinc@amc.edu.

Oley Calendar, March–October 2018

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

March 30: Nominations for Oley awards, applications for Kyle Noble Scholarship, and submissions for HomePN Research Prize due. *Note extended deadline!*

April 23–26: Oley exhibiting at National Home Infusion Association conference, Phoenix, AZ

May 6: Oley Regional Conference, Chicago, IL (tentative)

May 19–22: Oley exhibiting at Infusion Nurses Society, Cleveland, OH

September 15: Oley Regional Conference, Columbus, OH, in association with AVA conference (tentative)

September 15–18: Oley attending and exhibiting at Association for Vascular Access (AVA) conference, Columbus, OH

September 20–22: Oley attending and exhibiting at Pediatric Intestinal Failure Symposium, Pittsburgh, PA

October 5–8: Oley exhibiting at American College of Gastroenterology (ACG) Meeting, Philadelphia, PA

October 15: International HAN (Home Artificial Nutrition) Awareness Day

October 15–19: HPN Awareness Week

For updates on Oley regional conferences or if you are able to help at one of the Oley exhibits listed above, please contact Cathy at harrinc@amc.edu or (518) 262-5079. Watch for updates on Oley events at www.oley.org.

Additional Meetings of Interest

June 2–5: Digestive Disease Week, Washington, DC