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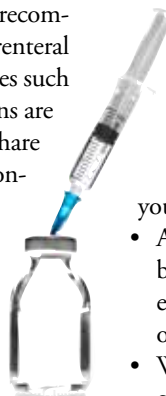
LifelineLetter

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

PN Product Shortages

As of early February, IV adult and pediatric multivitamins (sometimes referred to as MVI) were in short supply.* The American Society for Parenteral and Enteral Nutrition (ASPEN) has developed recommendations to help clinicians manage home parenteral nutrition (HPN) whenever IV product shortages such as this occur. These important recommendations are reviewed regularly, and are a great resource to share and discuss with your HPN team: www.nutrition-care.org/Guidelines_and_Clinical_Resources/Product_Shortages.

These recommendations include information that is critical for both short- and long-term HPN consumers, since there can be important health consequences if nutrients are missing from your PN. Ask your HPN clinician (nurse, dietitian, physician, etc.) and specifically your home infusion pharmacist to learn if you are affected by a shortage. If you are, ask if there is a plan in place to ensure you are getting what you need until the shortage is resolved.



Your home infusion pharmacist can help you better understand and become more familiar with ingredients that are listed on your HPN label. This may help you recognize if something looks different or is missing. If you do notice an unexpected change, contact the infusion pharmacist to review the bag's contents before infusing it.

Here are some ways you can advocate for yourself:

- Ask the infusion pharmacist to speak with you before any changes are made to your HPN, especially due to a nutrient or ingredient being on shortage.
- When any component such as multivitamins are on shortage, discuss the issue with your HPN clinician to ensure a plan is in place for an alternative method for getting vitamins (chewables or liquid vitamins perhaps) and for monitoring blood levels if necessary.

Drug Shortages, cont. pg. 14 ➤

Oley 2021

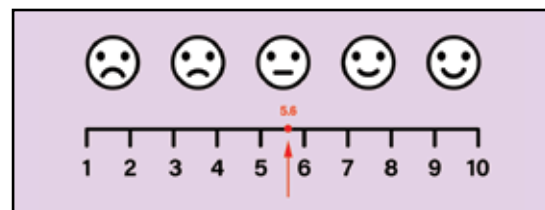
A Virtual Experience

Save the Dates! June 21–25

With much input from Oley members, **Oley 2021: A Virtual Experience** is taking shape. Mark your calendar and join us from June 21–25 as we host a series of educational programs with a different theme for each day. Sessions will run a maximum of four hours per day and include formal presentations and informal discussions, bringing the Oley Foundation community together for learning and connecting!

Please share your ideas for daily themes, presentation topics, speakers, etc. with Joan Bishop at bishopj@amc.edu and Andrea Guidi at andreaguidi.oley@gmail.com.

Watch your email inbox, the *LifelineLetter*, and www.oley.org for updates.



Reported mental health of HPN/HEN consumer, on a scale of 1 to 10, with 1 being the worst it's ever been and 10 being the best (see more, Q9, page 12).

Consumer/Caregiver COVID Survey, Fall 2020

The Oley Foundation surveyed consumer and caregiver members regarding their experiences with COVID-19 twice: once in April 2020, near the beginning of the pandemic in the United States, and again in late November. Thank you to the 349 consumers and caregivers who completed the fall survey.

To make the information easier to understand, we've provided the results that follow in the order of highest concern or relevance whenever possible. If you take in information better visually, we encourage you to view graphs of the results posted at www.oley.org/fallcovid19results. If

COVID Survey, cont. pg. 11 ➤

LifelineLetter

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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 healthcare provider prior to actual use. Correspondence can be sent to the Editor at the address above. Medical/scientific content contained herein has been peer reviewed by an Oley advisor or trustee.

Our Mission

...is to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

The Oley Foundation provides its 24,000+ members with critical information on topics such as medical advances, research, and health insurance. The Foundation is also a source of support, helping consumers on home IV nutrition and tube feeding overcome challenges, such as their inability to eat and altered body image. All Oley programs are offered **FREE of CHARGE** to consumers and their families.

Oley Foundation Programs

- *LifelineLetter*
- Peer to Peer Support
- Conferences and Webinars
- Resources to Promote Living Well on Tube Feeding and IV Nutrition
- Equipment Supply Exchange
- Advocacy and Awareness

Resource Spotlight:

With over 24,000 members—consumers, caregivers, medical professionals, industry representatives and more, all with a connection to home enteral and/or parenteral nutrition (tube feeding or IV nutrition, or HPEN)—the Oley Foundation is in a great position to represent the needs of this community to legislators, regulators, manufacturers (of medical devices and formula, for example), home care companies, other nonprofit organizations, and more.

On behalf of the community, the Oley Foundation

- advocates for legislation and rules that will help make HPEN and related care safer and more accessible;
- brings your voice to manufacturers involved with HPEN and related fields;
- raises awareness of HPEN;
- shares latest research and guidelines regarding HPEN;
- creates a network where HPEN consumers and caregivers can find support;
- and more.

Help us help you by sharing your thoughts and concerns with us; responding to action alerts when you are able; updating your Oley profile (call 518-262-5079 for help); participating in awareness events (even if it's just "liking" or "sharing" a Facebook post); reaching out to one another; and joining us for conferences and webinars. YOU are the Oley Foundation.

How to Support Oley

Donations are tax deductible and are accepted at www.oley.org/donations or at the street address on left.

Thinking About Summer Camp?

We've collected the names of several overnight summer camps in the U.S. that, to the best of our knowledge, will accept youth on tube feeding and/or IV nutrition (enteral and/or parenteral nutrition), and share them with you here. Please visit their websites or call to find out what programs they will be offering this year. If you know about other camps, please email us (oleyfoundation@gmail.com) and we'll add them to our list!

CALIFORNIA

The Painted Turtle*
Lake Hughes, CA
(661) 724-1550
www.thepaintedturtle.org

COLORADO

Roundup River Ranch*
Gypsum, CO 81637
(970) 524-2267
www.roundupriverranch.org

CONNECTICUT

Hole in the Wall Gang Camp*†
Ashford, CT
(860) 429-3444
www.holeinthewallgang.org

FLORIDA

Camp Boggy Creek*
Eustis, FL
(352) 483-4200
www.boggycreek.org

KENTUCKY

The Center for Courageous Kids
Scottsdale, KY
(270) 618-2900
www.thecenterforcourageous-kids.org

MICHIGAN

NorthStar Reach*
Pinckney, MI
(734) 680-8744
www.northstarreach.org

NEW YORK

Double H Ranch*
Lake Luzerne, NY
(518) 696-5676
www.doublehranch.org

NORTH CAROLINA

Victory Junction*
Randleman, NC
(336) 498-9055
www.victoryjunction.org

OHIO

Flying Horse Farms*
Mt. Gilead, OH
(419) 751-7077
www.flyinghorsefarms.org

PENNSYLVANIA

Camp Chihopi (Children's Hos.)
Pittsburgh, PA
(412) 692-6115
www.chp.edu/CHP/camp+chihopi

TEXAS

Camp John Marc
Busque County, TX
(214) 360-0056
www.campjohnmarc.org

Camp Summitt

Paradise, TX
(972) 484-8900
www.campsummittx.org

WASHINGTON

Camp Korey*
Carnation, WA
(425) 844-3100
www.campkorey.org

MULTIPLE LOCATIONS

Camp Oasis
Multiple locations: CA, CO, GA, MI, MN, MO, NY, PA, TX, WA, WI, WV
www.crohnscolitisfoundation.org/get-involved/camp-oasis

Epilepsy Foundation camps
Call (800) 332-1000 to find a camp near you
www.epilepsy.com/about-us/our-programs/camps



Tube feeder Gracelyn R. on horseback

FAMILY CAMPING OPTION

Camp Harkness
Waterford, CT
(860) 443-7818
portal.ct.gov//DDS/SouthRegion/Camp-Harkness/Camp-Harkness
Camp Harkness is a state-run park where only families that have a disabled/ill family member can rent a campsite or cabin. It does not provide care staff.

*A Seriousfun Network camp
†We are saddened to note that Hole in the Wall Gang Camp suffered significant fire damage in February 2021. Visit their website for updates.

Oley Tim Weaver Camp Scholarship

This \$1,000 camp scholarship, *sponsored by Fresenius Kabi, USA*, provides youth on home parenteral and/or enteral nutrition (HPEN) the chance to experience summer camp, building self-confidence, independence, courage, and creativity in a safe environment. Although summer activities remain in question because of COVID-19, we encourage you to apply at www.oley.org/campscholarship (applications accepted year 'round). *All 2021 camp scholarships will be honored in 2022 in the event of a coronavirus complication (i.e., camp closures, COVID-19 illness, self or mandatory quarantines, and so on).*

Tube Talk

Will be back next issue!



Abbott

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†Ingredients not genetically engineered.

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From the Desk of Joan Bishop, Executive Director

As I look back at the past year, I'm struck by the sheer weight of all we've been through. Most of 2020 activities reflected planning to adapt to limitations brought on by the pandemic. It's been a year of getting acquainted with new ways to serve the Oley community while staying safe.

We entered into the world of virtual platforms to meet and plan and host conferences with an added benefit of being able to reach members that we wouldn't have if gatherings were hosted face-to-face. Oley Ambassadors extended invitations to virtual support group meetings to include people from out of their areas. It's been amazing to witness how we have all found ways to adapt and thrive during these chal-

lenging times. I want to acknowledge a strong and committed Oley staff, amazing Ambassadors, strong Board of Directors and Advisory Council, devoted Corporate Partners, and everyone who shared an idea and helped in any way—all standing strong in support of our efforts.

It pleases me to acknowledge the financial underpinning that continues to keep Oley in forward thinking mode. We are grateful for Corporate Partner support, individual contributions, matching grants, Facebook fundraisers, gifts from donor sites like YourCause, and donations from online shopping sites.

One overriding factor gives me confidence, hope, and excitement as we move forward in 2021: our ability and desire to serve members despite all challenges.

As we begin a new year with hopes of returning to some form of "normalcy," I am anxious to see how we can build on what we knew prior to COVID-19 and combine this with all that we learned during the pandemic. It's bound to be a dynamic year! Our plans for 2021 include lofty goals! We will not only maintain our current (virtual) approach to meeting the needs of our community with an annual and multiple mini meetings, but increase the number of webinars offered, continue to build on the glossary, launch the Find a Clinician tool on www.oley.org, and celebrate Feeding Tube and Home Parenteral Nutrition (HPN) Awareness Weeks, to name a few things. I look forward to all that is ahead.

I encourage each of you to send along your suggestions: topics to be covered at the meetings and webinars or in the newsletter (along with suggestions for speakers or authors), etc. Oley is your organization so please stay tuned, and invest in our efforts.

I send best wishes and cheers to 2021 from the Oley staff, and thank you for everything that you do for each other.

Stay safe and healthy!

—Joan

Oley Member Joyce Madden Leaves Bequest

Joyce Madden, an Oley member since 1998, left a generous bequest to support Oley Foundation programs. She had been on tube feeding for many years before she passed away in September 2019.

Joyce lived in San Francisco, then Denver, where she worked as an artist for a greeting card company.

Joyce had many interests including football, computers, bowling, and photography. Her passion, however, was her painting and she was an amazing artist.

Joyce overcame profound health challenges and continued to live her life. We are grateful for the legacy she leaves for Oley members.



Joyce Madden

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cardinalhealth.com/Oley2020

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2021
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Nurses
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www.oley.org

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Join Us for a Mini Meeting

April 30, 2021 | 11:00 a.m.–4:00 p.m. EST

Formerly known as “Oley Regional Conferences,” these FREE one-day meetings offer you the opportunity to learn and connect as experts share the latest information, advocacy, and research. The conferences are coordinated for consumers and family members/caregivers, but all others are encouraged to attend and learn. All mini meetings will be held virtually until further notice.



Visit www.oley.org/Enrichmentprograms for details and to register!

Award Nominations Due 3/24

The Oley Foundation will present the following awards in 2021 to recognize those in our community who have earned our respect, inspired us, and taught us.

- **Innovator/Advocator Award**, Sponsored by *Avanos*
- **LifelineLetter Award**, HPN, Sponsored by *Nutrishare, Inc.*
- **LifelineLetter Award**, HEN, Sponsored by *Nestlé Health Science*
- **Child of the Year Award**, Sponsored by *Abbott*
- **Celebration of Life Award**

Visit www.oley.org/nominations for award criteria and the nomination form (due by **March 24, 2021**).

Awards will be presented during the annual conference, to be held virtually, June 21–25, 2021. Winners will receive a \$750 grant to attend the next in-person meeting, and will be spotlighted in the *LifelineLetter*. Recognition is given to all nominees.

Register for Public Policy Forum

The Digestive Disease National Coalition (DDNC) Spring Public Policy Forum, to be held virtually this year March 4–9, brings together patient advocates, healthcare providers, and industry and professional society representatives concerned with digestive diseases. Attendees, including Oley Foundation staff and volunteers, will hear from leaders in the digestive disease community, learn about key legislative issues impacting the community, and advocate for digestive disease research and improved patient care in virtual meetings with Capitol Hill congressional offices.



Don't think you can't make a difference as a “virtual advocate.” One of the DDNC's longstanding legislative priorities, the Removing Barriers to Colorectal Cancer Screening Act, was included in the recently approved government funding package, thanks to patients and professionals contacting their legislators remotely.

Register for the forum (no charge) at www.ddnc.org. If you have any questions, please contact Lisa Metzger with the Oley Foundation (metzger@amc.edu or 518-262-5079) or Jackson Rau at the DDNC (Rau@HMCW.org or 202-544-7497).



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Thank You for Your Support in Fiscal Year 2020!

The following list represents everyone who contributed toward Oley's efforts in our 2020 fiscal year: October 1, 2019, to September 30, 2020. ported Oley by volunteering their time and talents. Note: when three gifts are given in honor of, or in memory of, an individual or special Donations received October 1, 2020, or later will be acknowledged in next year's listing.

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

Steve Atkinson, includes matching gift from Johnson & Johnson

Ambassadors (\$2,000–\$4,999)

Lillian Harvey Banchik, in honor of the birth of her grandson, Hunter Harvey Banchik Morpeth; includes Facebook and Oley walk fundraisers
Hadar Birger-Bray**, includes Facebook fundraiser
Dale and Martha Delano
Tiffany Dodd**, includes Facebook and Oley walk fundraisers, and donation in memory of Ansley McCormick
Darlene Kelly**, MD, PhD

President's Circle (\$1,000–\$1,999)

Charlie Cleberg
Paul DeBarbieri
Anonymous
Nancy and Peter Kudan, in memory of the Klein Family
Diane Larsen
Brian McCall, in memory of Marie Latta and in honor of Rick Davis
Michael Medwar, includes Oley walk fundraiser
Nestlé Health Science, in honor of Joy McVey Hugick*, **

Alyce Newton, MS, RDN, LDN, CNSC, in memory of Gisela Barnadas, MS, RD
Francis and Joan Scheib, includes matching gift from the GE Foundation
Southern Rensselaer Rotary Club
Dan and Sheila Vander Sanden
Family Foundation Fund at the Greater Milwaukee Foundation, a grant from
Cathy and Brian Zbanek

Benefactors (\$500–\$999)

AmazonSmile Foundation
Heidi Andolina, includes Facebook fundraiser
Susanne and David Appel, in honor of Rebecca and Daniel Appel
Jane Balint, MD
Dr. John and Carol Broviac
Howard and Marcia** Denenholz, in honor of their 44th wedding anniversary
Gail Egan, MS, ANP, in memory of Don Young
Kenneth and Marilyn Freidman, in memory of Eilyne Levy
Colman Gulden
Heather Herrington
Joanne Hilferty
Lyn Howard**, MB, FRCP
Anonymous

Diane Juncker, in memory of Darnell Gardner
Anonymous
Brian Koenig, in honor of the 2019 Kyle Noble Scholarship recipient, Derick Goldsmith, "who is an inspiration to many"
Adam Koncius, in honor of Aidan Koncius
Lamont Engineers
The minds + assembly team
Katie and Robert Peters, includes Oley walk fundraiser
Fred Reuning and Jan Callison
Michelle Rosinek
Andrea and Rodney Schussler
Thomas and Barbara Squadere
John Wesley, MD

Sponsors (\$250–\$499)

Jodi Akst
Robert and Laura Andolina
Anonymous
Sandra Baldonado
Helene Banks, in memory of Michael Aklufi
Jon and Susan Becker
Bette Bond and the Bond Family, in memory of all the people who died this year, and in memory of Lynn Hamilton
Erin Castelloe, in honor and memory of Michael Aklufi
Dr. Stanley Caulder, in memory of Zoe Allison Caulder Hartley
Dan Dietel and Kathleen Jackson, in honor of Jackson Merrill Dietel
Rebecca Edwards, includes Facebook fundraiser
Michelle Fogle, includes Facebook fundraiser
Todd and Susan Friedman, in honor of Susan "being there 24/7 during rare TPN complications," of Michael Medwar's 50th birthday, and in memory of David Young
Helen Grimes, in honor of Jennifer Mason
M. T. Hirschler
Rose** and Jeff Hoelle, in memory of Alisha Hoelle
John Hutchinson and Dr. Kathy Platoni
Candace Jackson, includes Facebook fundraiser
Phil Kellerman***

Thomas and Ali LeBlanc
Kathy Mannino, in memory of Clarence ("Oley") and Kay Oldenburg
James and Barbara McCoy
David McGee
Lisa*** and Ron Metzger, in honor of Dr. Lyn Howard, and in memory of the Oley members we've lost and who have left such an impression, and of Dr. Werner (Bill) Berglas; includes Oley walk fundraiser and matching gift from National Grid
Anonymous, in memory of Richard M. Harris
Marc and Natalie Packman
Carol Rees Parrish, MS, RD
Lynn and Kurt Patton
Adam and Robin Roberson
Douglas Seidner, MD
Danny Sekelsky
Tavilla Market Associates
Anonymous
Drs. Santhi and Kanaka Vege
Marion Winkler, PhD, RD, LDN, CNSC

Patrons (\$100–\$249)

Lhoidz Amores, includes Facebook fundraiser
Ivania Angermeyer
Dianne Archer, includes Facebook fundraiser
John and Judith Arruda
Ronald and Lucille Ayotte
Linda Bedian
Thomas Behrendt and Lisa Kaston, in honor of Phil*** and Ed Kellerman
Michael and Vicky Bergath
Paul and Karen Berge
Nancy Bitton, in honor of Natalie Rosenthal
Lynda and Tom Bosworth, in honor of "all warriors and caregivers! And in memory of the smartest, funniest guy we've met, Martin Koenig"
Anonymous
Juliette Bren
Gail and Chuck Brennenstuhl
Neil Brenner
Jean D. Brown
Richard and Rosemary Brown
William Brundage
Janet Butler
Philip Buttling

Special Shout Outs

To those who supported the Oley Foundation in FY2020


- with **in-kind gifts**: Timothy Arends/Dorsey & Whitney LLP; Abbott; Avanos; Functional Formularies; Al and Kathy Bain; Roy George; Madalyn George-Thiemann; Maddie Hicks; MagicWig Productions, Inc.; John Mahalchak; Mike McCarthy; Kendall Renee; Malik Saunders; Alan Segal
- through purchasing at **AmazonSmile** and via **YourCause**
- via **Facebook** donations and campaigns by: Lhoidz Amores; Anonymous (multiple); Heidi Robertson Andolina; Dianne Archer; Lillian Banchik and Brenda Gray; Hadar Birger-Bray; Ellie Brock; Francesca Cirillo; Tiffany Dodd; Chelsea Edwards; Michelle Fogle; Roy George; Damarius Noelle Ingram; Candace J. Jackson; Richard Noble and Kelsey Wessa; Kate Thunberg O'Connor; Joanne Platt; Malik Kaume-Dau Saunders; Ally Winter; Jim Wittmann; Dan Wolfe
- through **volunteering**, including our Oley Ambassadors

We also want to thank those who are not listed below, yet have supported, we've created a separate list, which can be found on pages 9–10.


Stephen Campbell, in memory of
Lori Ann Campbell
Todd Canada
Jean and Ted Carmone
Dr. and Mrs. Charles Carozza
Cathy Christopher
Steve Cohen
Michael Corrado
Bianco Dale
Todd Dalton
Matt Davis
Stephanie De Abreu
Lauren DeMinico
Ari Dennis, includes Oley walk
fundraiser
Dr. and Mrs. Stanley Dudrick
Diane Duke
Debora Duro, MD, with thanks to
the Oley Foundation "for all you
do for these patients"
Eastwick Foundation
Terry Edwards
Mr. and Mrs. John Eidem, in
memory of Charlie Eidem
Miriam Feller, in honor of Hadar
Birger-Bray**
Chris French, Nick Distefano, Ryan
Petersen, and Charles Lodge
Stuart Gordon, in memory of
Irmagail Gordon
Brenda Gray, includes Facebook
and Oley walk fundraisers
Thomas Gulden
Karen Sexton Hamilton, MS, RD,
LD, CNSC, in honor of HPEN
consumers and families
Judy and Pat Hanlon
Judith Hanson
Marta Harshbarger, in memory of
Arthur and Marjorie Harshbarger
Greg Henderson
Richard Hubbell
Carol Ireton-Jones, PhD, RDN,
LD, CNSC, FASPEN, FAND, in
memory of Nina L. Ireton, and
Debbie Fox, RD, a long-time
HPN consumer, expert Regis-
tered Dietitian, and friend
Harlan Johnson
Susanne Karacki, in memory of
Larry Karacki
John Kerner, in memory of Susan
Denise Kerner
Jill and Jake Krautkremer
Mary and Charles Kunz

William Langford
Deborah Lechtman
Johanna and Lloydanne Leddy
Anonymous
Al Mackay
Mercedes Maks
Richard Manning
Marcia Martin, in memory of
Eleanor Orkis
Theresa and David Mathiasmeier
Eli and Joan Medwar
Arvil Miller
Anonymous
Gerald Murphy
Lynn Murphy
Anonymous, "in honor of my col-
leagues working hard every day
to educate clinicians and better
the lives of patients on parenteral
nutrition"
David Nierenberg
Bob, Missy, and Matt Norris
Danielle Norris
Jason O'Connor, in honor of Sam;
includes matching gift from
American Family
Kate O'Connor, includes Facebook
fundraiser
Oley Foundation staff, in memory
of Dr. Stanley Dudrick
Stephen, Patricia, Erin, Ryan and
Kevin Ormerod
Lou and Martha Pacilio
Ellen Pierce, in memory of Jeff
Dutton, Paula Southwick, Bob
Sweet, Elizabeth Tucker, and
John Tucker
Joanne** and John Platt, includes
Facebook fundraiser
Real Food Blends
Donald Riccio
Karen Rieck, in memory of Gary Rieck
Anonymous
Dina Rosen
Carolyn and David Rowland
Mary Salerno, in honor of
Stephanie Salerno
Malik Kaume-Dau Saunders, in-
cludes Facebook fundraiser
Anonymous, in memory of Pat Brown
Cindy and Erik Shten**, in honor
of Dr. Lyn Howard***
Vi Schultz
Arthur Senra


Donors, cont. pg. 8



"It's important to find a network
of people who have been through this—
people with whom you don't have to be
anything, but who you are."
PEGGY, GATTEX PATIENT



Like us on Facebook and join the community
[Facebook.com/GATTEX](https://www.facebook.com/GATTEX)



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Donors, from pg. 7

Dina Sevayega
Robert Shulman, in honor of Phil Kellerman***
Bob and Mary Smithers**
Sheldon Sokol
Heather Springer
Ezra Steiger, MD
Eileen Steinvurzel
Anonymous
Steve and Edithe Swensen
ThriveRx, in memory of Caroline Mitter and Deborah Myers
Thomas Bryan Tims
Cathy Tokarz, in honor of Bettemarie Bond** and family, Todd and Susan Friedman, and Michael Medwar and family
Jennifer Trask
Heather Turk
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Donors, cont. pg. 10




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Reference: 1. Silverman, E. Why the price of dehydrated alcohol is going from \$1300 to \$10K. Stat News. <http://www.statnews.com/pharmstat/2020/02/12/dehydrated-alcohol-ophan-drugs-price/>. February 12, 2020. Accessed September 19, 2020.
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Needed: Your Email Address

If Oley doesn't have your email address, you're missing conference news, event invitations, HPEN FDA Alerts, and other timely updates. Remedy this today: email harrinc@amc.edu.

COVID Survey, from pg. 1

you have questions or comments, or would like to see more of the data or comments, email Roslyn Dahl at dahlr@amc.edu.

One of the most significant takeaways we found was the enormous challenge COVID-related isolation presented for consumers and caregivers. It was ranked the most challenging non-healthcare-related issue, and it affected the most respondents. Numerous respondents listed isolation and/or loneliness as an issue in other questions as well—including under healthcare-related challenges and quality of life issues, and as affecting the mental health status of the consumer and caregiver.

While we fully appreciate that nothing can take the place of in-person gatherings, we encourage members to reach out to Oley staff and one another via calling, texting, meeting virtually, and attending Oley meetings, support groups, and social events. (For details go to www.oley.org or Oley's Facebook page.) If you are interested in connecting with another member who is on tube feeding or IV nutrition (or helps care for someone who is) and has a similar diagnosis or interest/hobby, check out the list of volunteer ambassadors at www.oley.org/ambassadorsmain, or call the Oley office at (518) 262-5079 and we'll do our best to find you a match.

We hope you find the survey results illuminating!

Q1. What are your biggest healthcare-related challenges due to COVID at this time? Rank 1 to 5, with one being the least problematic and 5 being the most problematic; or N/A if it's not a problem at all.

Note: The averages (\bar{x} =average) include only respondents (n=number) who consider the issue at least a little challenging. (N/A [not applicable] responses were not factored into the averages.) For example, twenty-one respondents found getting a visit with their primary care physician (PCP) challenging, but only mildly so; on a scale of 1 to 5, the average of the rankings among those twenty-one respondents was 2.09. The "summary of comments" presents prevalent themes among the respondents' comments, and the number of people who included that theme in their comments.

- Avoiding getting COVID (\bar{x} =3.76, n=141)
- Hospitalization—general (\bar{x} =3.49, n=90)
- Hospitalization—lack of an advocate (\bar{x} =3.46, n=81)
- Other (\bar{x} =3.37, n=22)
- Outpatient treatment (tube change, infusion, etc.) (\bar{x} =2.97, n=55)
- Specialist Physician visit (\bar{x} =2.78, n=52)
- COVID disease symptoms, complications and/or management (\bar{x} =2.57, n=32)
- Homecare services (\bar{x} =2.51, n=34)
- Mental Health Professional visit (\bar{x} =2.38, n=15)
- Homecare supplies (\bar{x} =2.22, n=27)
- Primary Care Physician visit (\bar{x} =2.09, n=21)

Summary of Comments:

Isolation (n=16); fear of exposure (n=15); delayed doctor appointment/medical treatment (n=8); depression/mental health (n=8); supplies (n=8); no visitation policies (n=4); had COVID (n=3); other (n=2): insurance, loss of job/income, multiple diagnoses/therapies, overworked healthcare system, trouble getting COVID testing, stress.

Q2. What kind of advocacy resources would be most beneficial to you during hospitalization if your friend/family/caregiver is not available to support you?

- Hospital-employed patient advocate (42.7%)
- Advocate from a non-hospital organization (36.1%)
- Homecare provider clinical liaison (32.8%)
- Easier access to a social worker (27.2%)
- Other (9.7%)

Q3. What are your biggest non-healthcare-related challenges due to COVID at this time? Rank 1 to 5, with one being the least problematic and 5 being the most problematic; or N/A if it's not a problem at all.

Note: The averages (\bar{x} =average) include only respondents (n=number) who consider the challenge at least a little problematic. (N/A responses were not factored into the averages.) For example, 161 respondents found isolating themselves from friends and family to be very challenging; on a scale of 1 to 5, the average of the rankings among those 161 respondents was 3.88.

- Isolation from friends and family (\bar{x} =3.88, n=161)
- Changes in schooling for kids (\bar{x} =3.68, n=56)
- Other (\bar{x} =3.48, n=21)
- Shopping for necessities (\bar{x} =3.11, n=54)
- Loss of income (\bar{x} =3.08, n=66)
- Needing to work outside the home (\bar{x} =3.06, n=32)
- Entertainment/distractions (\bar{x} =2.88, n=53)
- Working from home (\bar{x} =2.04, n=12)

Summary of Comments:

Isolation (n=11); financial issues (n=4); difficulty traveling/shopping (n=4); other (n=2): entertainment/boredom, lack of visitation policies, religious services halted, fear of exposure, discrimination, can't wear mask, mental health, depression, schooling from home, therapies.

COVID Survey, cont. pg. 12

Sneak Peek at Webinars

Free of charge | www.oley.org/webinars

March 2021 (exact date TBA) | 1:00 – 2:00 pm, EST

Interview with Allysa Seely, Team USA paratriathlete on HPN, and her sports dietitian, Jacque Scaramella, MS, RD, CSSD

April 6, 2021 | 1:00 – 2:00 pm, EST

Discussion on the Patient and Physician Perspective with Dr. Paul Wischmeyer, Anesthesiologist, Critical Care Specialist at Duke University Hospital and HPEN consumer

July 13, 2021 | 1:00 – 2:00 pm, EST

Motility Disorders Discussion with Dr. Carlo Di Lorenzo, Chief of the Division of Pediatric Gastroenterology, Hepatology and Nutrition; Nationwide Children's Hospital



COVID Survey, from pg. 11

Q4a. Rate how you feel about your participation in telehealth visits.

- Easy (52%)
- Moderate (29%)
- Difficult (15%)
- N/A (5%)

Q4b. Which factors do you find challenging about telehealth visits?

- Having strong/dependable internet service (31%)
- Using the telehealth software/platform (27%)
- Other (26%)
- N/A (23%)
- Setting up appointments (13%)
- Using your computer/device (17%)

Summary of Comments:

Symptom/physical representation (n=21); communicating (n=12); personal connection, trust (n=11); internet/technology (n=9); difficulty concentrating (n=5); pre-appointment testing and/or paperwork (n=5); privacy/distractions at home (n=5); other (n=≤2): lack of consistency between providers, delayed appointments, too expensive.

Q5. On a scale of 1 to 5, rate how you feel about Oley advocating to keep insurance coverage for telehealth visits after the pandemic, with 1 being not important and 5 being very important.

- 4.5

People felt advocating for continued coverage of telehealth visits was important to (1) reduce costs for routine follow-up visits; (2) save money and time on travel; and (3) decrease exposure to germs.

Keeping the option of face-to-face visits was important, too, for patients who feel the quality of in-person care is better and necessary for some appointments.

Q6. Has your area been considered a hotspot for COVID at any time since March of 2020?

- Yes (71%)
- No (18%)
- I don't know (11%)

Q7. What measures are you taking to protect yourself/your family from infection with COVID-19?

- Wearing a mask (96%)
- Socially distancing (96%)
- Avoid gatherings of 10+ people (86%)
- Minimizing in-person shopping (81%)
- Limiting social activities to outdoor venues only (62%)
- Working from home (32%)
- Using PPE other than a mask (31%)
- Taking classes online instead of in-person (28%)
- Other (18%)
- None of the above (2%)

Summary of Comments:

Staying home (n=34); practicing hand hygiene (n=7); restricting the number of visitors (n=6); getting grocery delivery/pickup (n=4); sanitizing (n=4); other (n=≤2): homecare uses PPE, telehealth, air filter,

COVID testing regularly, following doctors' recommendations, extra mental/physical care, N95 or medical masks, no changes to daily routine.

Q8. What level of impact has COVID-19 had on your quality of life (for example, socializing, shopping, travel, exercise, dealing with long-term COVID symptoms), where 1= no impact, and 5= severe impact?

- 4.0

QoL Issues COVID Has Affected:

Isolation family/social (n=25); fear of exposure (n=6); financial stress/loss of income (n=4); stress/mental health (n=4); shopping (n=4); travel (n=3); other (n=≤2): reduced medical care, stress/mental health, hospitalization, supplies, reduced caregivers, entertainment, exercise, long-term COVID symptoms.

Q9. Rate the mental health of the person in your household on home IV nutrition (HPN/TPN) and/or home tube feeding (HEN), on a scale of 1 to 10, with 1 being the worst it's ever been and 10 being the best it's ever been.

- 5.6

How the Consumer Is Feeling:

Lonely (n=46); anxious (n=24); depressed (n=16); frustrated and/or angry (n=13); stressed/PTSD (n=13); fears exposure (n=11); financially stressed (n=6); in therapy (n=4); other (n=≤2): showing regression/lack of development, reduced mental health, medically stressed, reduced motivation, grieving, hopeless, low quality of life, considering self harm, increased symptoms.

Q10. Rate the mental health of the caregivers in your household, on a scale of 1 to 10, with 1 being the worst it's ever been and 10 being the best it's ever been.

- 5.4

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How the Caregiver Is Feeling:

Stressed (n=34); overwhelmed (n=19); fears exposure (n=17); isolated (n=16); depressed (n=14); anxious (n=13); tired (n=9); overworked (n=8); financially stressed (n=5); other (n=≤2): discontent, generally struggling, feels helplessness, in despair, frustrated, in therapy, bored, experiencing self-doubt, not exercising, fears limited supplies.

Q11. How are you planning to handle the holidays during the pandemic?

- I will celebrate just with my household (no outside family or friends) (n=208, 59.6%)
- I will celebrate virtually with my family and/or friends (n=77, 22.1%)
- I will celebrate with a smaller group than usual (n=59, 16.9%)
- I am cancelling my usual holiday plans and celebrating alone (n=51, 14.6%)
- Not sure yet and this is an ongoing discussion with family/friends (n=45, 12.9%)
- I will celebrate with the same people but with appropriate COVID-19 precautions (n=41, 11.8%)
- I am not changing my plans (n=33, 9.5%)
- I am changing the day in which we celebrate to ensure appropriate COVID-19 precautions are taken (n=16, 4.6%)

Q12. Have you or anyone in your household contracted COVID-19?

- Yes (9%)
- No (90%)
- Prefer not to answer (0%)

Q13. Does the person diagnosed with COVID have any NEW long-term health challenges as a result?

Loss of taste/smell (n=2); other (n=1) bronchitis, vertigo, respiratory, cardiac concerns, fatigue, worsening of pre-existing condition, and

“He never recovered. He is still overwhelmed by [multiple debilitating] symptoms.”

Q14. I am a/an...

- Adult on home parenteral nutrition/HPN (n=110, 31.5%)
- Adult on home enteral nutrition/HEN (n=66, 11.5%)
- Caregiver of an adult on home parenteral nutrition/HPN (n=40, 4.3%)
- Caregiver of an adult on home enteral nutrition/HEN (n=15, 12.3%)
- Caregiver of a child on home parenteral nutrition/HPN (n=43, 11.8%)
- Caregiver of a child on home enteral nutrition/HEN (n=41, 9.7%)

Q15. What geographic area do you live in?

- Great Lakes: IL, IN, MI, MN, OH, WI (n=69, 19.8%)
- Southeast: AL, FL, GA, MS, SC, PR (n=54, 15.5%)
- Midsouth: DE, DC, KY, MD, NC, TN, VA, WV (n=37, 10.6%)
- Northeast: NJ, NY, PA (n=36, 10.3%)
- Far West: CA, HI, NV (n=28, 8.0%)
- South Central: AR, LA, OK, TX (n=27, 7.7%)
- New England: CT, ME, MA, NH, RI, VT (n=25, 7.2%)
- Midwest: IA, KS, MO, NE, ND, SD (n=23, 6.6%)
- Mountain West: AZ, CO, ID, MT, NM, UT, WY (n=20, 5.7%)
- Northwest: OR, WA (n=19, 5.4%)
- Outside the United States (n=11, 3.2%)

Q16. Is the area where you live considered to be...?

- Suburban (58%)
- Rural (24%)
- Urban (19%) ¶



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Bill, Option Care Health nutrition patient

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Congratulations Maggie!

Maggie E.-V. won the Oley COVID Survey drawing for a \$100 gift card!

When we passed along the happy news, Maggie shared, “Oley is constantly striving to bring this community the best information and I’m so grateful that they even offered a survey, let alone rewarding me for helping them help us!”



Maggie E.-V.

Corporate and Foundation Program Support

Thanks to the following corporations, foundations, and organizations for their generous gifts (\$500+) for specific Oley programs in FY 2020. These gifts extend support beyond their corporate partner pledges.

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Drug Shortages, from pg. 1

For current information on drug shortages, visit:

- FDA Current and Resolved Drug Shortages: www.accessdata.fda.gov/scripts/drugshortages (for IV multivitamins, search “multi-vitamin infusion”)
- American Society of Health-System Pharmacists (ASHP) Drug Shortages: www.ashp.org/Drug-Shortages/Current-Shortages (for IV multivitamins search “multiple vitamins for infusion”)

ASPEN is continually addressing the ongoing shortage of IV multivitamins by working with and maintaining communications with the FDA, pharmaceutical manufacturers, other professional healthcare organizations, and clinicians to stay up to date on the status of the shortages, to collaborate to resolve shortages, and to provide resources for managing shortages.

*We (the Oley Foundation) have heard that the experiences of individual HPN consumers in regard to IV multivitamins over the past months have varied greatly. This can happen for many reasons, including individual diagnoses, availability of vitamins, how much supply your home care company has on hand, etc.

Our thanks to the ASPEN Public Policy Committee for their review and contributions.

Notable Individual Gifts

Among the 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 13, 2020–January 20, 2021.

Memorials: *In memory of* Beverly Akers; Nancy Backinger; Pat Brown; Sam Casperson; Ann DeBarbieri; Clifton Dodge; Dr. Stanley Dudrick; Charlie Eidem; Howard Goldmacher; Irmagail Gordon; Bruce F. Groeber; Linda Gulden; Richard Harris; Arthur and Marjorie Harshbarger; Catherine Henderson; Susan Herman, “who, as John Wesley’s long-term patient, helped develop the practical techniques of home parenteral nutrition”; Alisha Hoelle; Marilyn Huebner; Joyce Hydorn; Pamela Jenkins; Larry Karacki; Dorothy Kelly; Shirley, Arnold, and Fred Klein; Joyce Madden; Rick McDaniel; Pat Mielke, 18 years on HPN; Jonathan Miller; Leslie W. Noyes; Clarence and Kay Oldenburg; Eleanor Orkis; Mary Patnode; Gary W. Rieck; Kenneth Rosenhek; Dr. Barry and Sharon Sakowitz; Mary and Clayton Strain; Doug Vonstein; David Young; Don Young

Tributes: *In honor of* Julie Andolina, “thank you for your kindness”; Rebecca Appel and Daniel Appel; Hadar Birger-Bray; Joan Bishop; Lynda Bosworth; Bill and Sally Bowers; Michael William Cabral; Charlie Cleberg; Coram’s Corporate RD team—Sharon, Kristy, Katy, Heather, Barbara, Salli, Heather, Jessica, Sarah, Erin and Nicole; Mary Ellen Costa; Roslyn Dahl; Katie Dart, “for helping connect her patients to donated formula”; Mike Deciutiis; John R. Eaton; Morgan Goodrich, “she is a fighter and continues to blow us away with her strength and grace”; Dr. Lyn Howard; Carol Ireton-Jones; Phil Kellerman; Mark Kimmell, “for his regular donations of formula

to the Metro Atlanta community”; Barb Klingler, 34 years on HPN; Aidan Koncius; Michael L. Levin; Kady Limbrunner; Philip Lindensmith; Kevin Long; Alexander Mackay; Jennifer Mason; the Larry Mayer Family; Jeff Nemeth, who “needed a feeding tube and really did not like it, but Oley helped him through it; he prevailed, and is now healthy and had the tube removed”; the Oley Foundation’s first virtual conference and walkathon; Carol Rees Parrish and Team Copeland at UVA; Lynn Patton and her retirement; Nancy Pickett, the 2020 Kyle Noble Scholarship winner, and her efforts to make a positive impact on others; Zeke Retsinas and family, the 559th to receive a Superhero Experience from the Colten Cowell Foundation; Ryan’s 16 years on HPN; Dr. Wendy Stock, “for her tireless devotion to the treatment of leukemia, her loving support for all patients and their families, as well as her endeavors to research potential targeted therapies for greater overall survivals”; Bryan Tims

Matching Gifts: Microsoft; Saratoga Water Services, Inc.; VISA

Fundraisers: AmazonSmile Foundation; Facebook: Tiffany Dodd’s, Becky Reil’s, and Ally Winter’s birthday campaigns; and Bob Smithers’ Giving Tuesday campaign; Phil Kellerman’s ongoing political memorabilia fundraiser on eBay

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.

Thank You Corporate Partners!

Please join Oley in thanking the companies that support us year round. Learn more about our most recent corporate contributors in their own words below. For a complete list of corporate partners go to www.oley.org/PartnerShowcase.

Abbott

Abbott is a global healthcare leader that helps people live more fully at all stages of life. Its portfolio of life-changing technologies spans the spectrum of healthcare, with leading businesses and products in diagnostics, medical devices, nutritionals and branded generic medicines. Its 107,000 colleagues serve people in 160+ countries.

Fresenius Kabi

Fresenius Kabi is a leading global healthcare company that focuses on pharmaceuticals and medical devices used to care for critically and chronically ill patients inside and outside the hospital. Fresenius Kabi products include intravenous specialty and generic medicines, transfusion technologies, infusion therapies, clinical nutrition, and related medical devices.

Zealand Pharma

Zealand Pharma is changing patients' lives with innovative peptide therapeutics. Patients inspire the company to provide the best possible solutions for gastrointestinal and metabolic disorders. The company is building upon twenty years of expertise in developing treatments for patients with short bowel syndrome.

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 B. 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 Schesnol</i>
<i>David & Sheila DeKold</i>	<i>Darlene Kelly, MD, PhD</i>	<i>Doug Seidner, MD, FACG, 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>Joyce Madden</i>	<i>& Gregory A. Thompson, MD, MSc</i>
<i>Herb & Joy Emich</i>	<i>Hubert Maiden</i>	<i>Cathy Tokarz</i>
<i>Jerry Fickle</i>	<i>Laura Matarese, PhD, RD,</i>	<i>Eleanor & Walter Wilson</i>
<i>Don Freeman</i>	<i>LDN, CNSC, FADA, FASPEN</i>	<i>Marion & Larry Winkler</i>
<i>Linda Gold</i>	<i>Kathleen McInnes</i>	<i>James Wittmann</i>
<i>Linda Gravenstein</i>	<i>Michael Medwar</i>	<i>Patty & Darrell Woods</i>
<i>Deborah Groeber</i>	<i>Meredith Nelson</i>	<i>Rosaline Ann & William Wu</i>
	<i>Nancy Nicholson</i>	

Oley Corporate Partners

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

TITANIUM LEVEL PARTNER (\$150,000+)

Takeda Pharmaceutical

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

9 Meters Biopharma

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Coram / CVS Specialty Infusion Services
Nutrishare, Inc.

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

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Option Care
Optum Infusion Pharmacy
Zealand Pharma

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

Nestlé Health Science
Real Food Blends
VectivBio

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

Applied Medical Technology, Inc.
Cook Medical
MOOG Medical
Soleo Health

2021 Oley Calendar

COVID-19 has changed how we meet and exchange information. Many of the conferences we usually list in our calendar have been rescheduled, canceled, or moved to a virtual platform. Dates and venues for events in 2021 are, in many cases, still undecided. Please check the Oley or other appropriate website for the most up-to-date information.

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship. Note: *scholarships will be honored at a later date in the event of a coronavirus complication (i.e., camp closures, COVID-19 illness, self or mandatory quarantines, etc.).*

Through May 15: Marketplace Health Insurance Special Enrollment Period. Enroll in or change plans. Visit www.healthcare.gov.

March 2021 (exact date TBA): Oley webinar "Interview with Alysa Seely, Team USA paratriathlete on HPN, and her dietitian, Jacque Scaramella"

March 1 (and then the first Monday of every month): Young adult support group, virtual, 5:00 pm EST

March 4 (and then the first Thursday of every month): Philadelphia Suburbs Tube Feeding/HPN Support Group, Blue Bell, PA, more info @ www.oley.org/SupportGroups. Meetings will be virtual until otherwise indicated.

March 4–9: Oley participating in Digestive Disease National Coalition (DDNC) Spring Public Policy Forum, virtual

March 24: Deadline for Oley Award nominations, Kyle R. Noble Scholarship applications, and Home Parenteral Nutrition Research Prize submissions

March 25 & April 29: Oley Kidz Klub, virtual

April 6: Oley webinar "Discussion with Dr. Paul Wischmeyer; Patient and Physician Perspective"

April 15: Oley Tube Feeding/TPN Support Group for Patients and Caregivers, virtual

April 30: Oley Mini Meeting, virtual

June 21–25: Oley 2021: A Virtual Experience

July 13: Oley webinar "Motility Disorders Discussion with Dr. Carlo Di Lorenzo"

October 11–15: HPN Awareness Week

For more information, email harrinc@amc.edu or call (518) 262-5079.

Additional Meetings of Interest

March 20–23: ASPEN 2021 Nutrition Science & Practice Conference, virtual

April 19–22: National Home Infusion Association (NHIA) conference, virtual

May 21–23: Digestive Disease Week, virtual

June 7–10: Nutrition 2021 (American Society for Nutrition conference), virtual

June 23–26: United Mitochondrial Disease Foundation (UMDF) conference, Charlotte, NC

June 30–July 3: Congress of the Intestinal Rehabilitation and Transplant Association (CIRTA), Auckland, New Zealand

September 16–19: AVA 2021, Orlando, FL