Progress Towards a New Treatment for IFALD
Alan L. Buchman, MD, MSPH, Professor of Clinical Surgery, University of Illinois at Chicago Medical Director, Intestinal Rehabilitation and Transplant Center, UI Health

Intestinal failure–associated liver disease (IFALD) was formerly called “parenteral nutrition–associated liver disease,” before it was recognized that, in those with intestinal failure and liver disease, malabsorption plays an important role. It is thought that other factors, such as infections, may also play a large role, along with parenteral nutrition (PN).

What is IFALD? Is it a disease? How do we define it?
IFALD is a serious complication of intestinal failure and remains the most common indication for liver/small intestine transplant and isolated intestinal transplant, as well as a significant cause of death in those who develop liver failure and are not candidates for transplantation. It has often been classified under nonalcoholic fatty liver disease (NAFLD/NASH—the most common form of liver disease in the U.S.), but in reality, IFALD is much different, and is a disease in its own right—and it is much more serious than NAFLD.

Diagnosing IFALD
In order to establish a diagnosis of IFALD, other etiologies of liver disease, such as infectious hepatitis, drug-induced hepatitis, alcohol, and chronic biliary obstruction, need to be excluded. In general, in the absence of any of these conditions, when there is a persistent elevation of liver enzymes (AST, ALT, alk phos, and/or GGT at least 50 percent greater than the upper level of normal over a period of at least six months in adults or six weeks in infants), IFALD can be diagnosed.
IFALD is characterized by two different, but simultaneous histologic findings in the liver when a biopsy

IFALD, cont. pg. 4 ➔

Save the Dates!
June 21–23, 2020
Newport Beach, California

Updates Posted:
• www.oley.org/AnnualConference
• the Oley Foundation Facebook page

Help Plan the Program!
Planning for the conference program is underway but it’s not too late to send in your suggestions for topics to be covered and/or recommendations for speakers. Together we can work towards planning the best conference ever!

To Be or Not to Be: My Death Wishes
Looking at advance directives
Michael Levin
Extracted from Tube Life (forthcoming), with minor edits and permission of the author.

I’m a real control freak, but ever since I started planning for my death—the lawyers call it “estate planning”—I’ve been faced with the conundrum of what to do about my beloved feeding tube, my life-line. Many people have to decide whether they want
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 22,000+ 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: Meeting Others

There is value in meeting and talking to others who are going through something similar to what you are experiencing. It can help lessen feelings of loneliness and isolation; it can help reduce stress and anxiety; it offers a chance for you to talk openly about things others will understand without you having to offer a long explanation. You can learn how others handle challenges or day-to-day life, about valuable resources, about options that may be available to you.

Meet others at support groups led by Oley Ambassador volunteers, at the Oley annual conference, or at Oley one-day regional conferences. More information at:

- [www.oley.org/SupportGroups](http://www.oley.org/SupportGroups)
- [www.oley.org/AnnualConference](http://www.oley.org/AnnualConference)
- [www.oley.org/oleyregionals](http://www.oley.org/oleyregionals)

How to Support Oley

Donations are tax deductible and are accepted at www.oley.org/donations or at the street address on left.
Welcome Julie, Our Newest Ambassador

Would you like to speak with someone who has “been there, done that”? Call an Oley Ambassador. For a complete list of Ambassadors, visit www.oley.org or call (518) 262-5079. Note: Ambassadors volunteer to provide peer support for HPEN patients and family members. They are not medical professionals and do not offer medical advice. Please do not contact Oley Ambassadors for solicitation, marketing, or research purposes.

Meet our newest Oley Ambassador!

Julie Andolina

Julie was born in 2000 with a congenital diaphragmatic hernia. After undergoing surgery at just two days old, she suffered a mid-gut volvulus, resulting in another surgery, the loss of a portion of her small intestine, and the diagnosis of short bowel syndrome.

Throughout her lifetime, Julie has undergone eight major abdominal surgeries, multiple IV catheter placements and replacements, and the diagnosis of d-lactic acidosis, a rare complication related to short bowel syndrome.

Despite being on home IV nutrition (HPN) and tube feeding (enteral nutrition), Julie was a very active child who dabbled in a multitude of hobbies: dance, gymnastics, art, reading and writing, piano, voice, theater, softball, and, later on, tennis and tae kwon do. In 2015, after years of hard work, she earned her first degree black belt, further proving to herself that she could do anything she set her mind to. Her loving and supportive mother, Heidi, used to tell her, “You can let yourself be Julie with the medical condition, or you can just be Julie.” She has consistently chosen the latter, never letting her diagnosis hold her back, and always trying to live her life to the fullest.

Now, at almost twenty years old, Julie’s health has stabilized enough that she no longer needs HPN, though she still has a g-tube for nightly enteral feeds. Julie says, “It’s time to start giving back to the Oley Foundation and its members, who helped support me and my family from the day I was born.”

Julie lives in upstate New York, not far from the Oley Foundation office, and joined the Oley Foundation staff in 2019 as an intern. You can reach her at julieandolina.oley@gmail.com or (518) 698-7549.

Need a Restroom Urgently?

Many members have experienced the need to get to a toilet immediately. This can be uncomfortable when you are at a store that doesn’t have a public restroom. Showing an employee the Oley Bathroom Access Card can make it easier to ask permission to use the restroom. The card reads: “I have a digestive disorder that means sometimes I need the bathroom urgently. Please allow me to use your facilities.” Order your FREE card at www.oley.org or by calling (518) 262-5079.

On Tube Feeding in the Greater Vancouver Area?

Adult home tube feed users are not tracked within Fraser Health Authority (Greater Vancouver Area, BC, Canada). Rebekah Sandhu, a clinical dietitian at Fraser Health Authority, is leading a research project to learn about the experiences and challenges of adults living in that area with home tube feeding and their caregivers. This information will be used to improve healthcare services.

What is required?

One in-person interview (60 minutes) at a location of your choice (your home or local hospital).

Who Can Participate?

People who use, or caregivers for people who use tube feeding for nutrition, or have in the past, who live at home in the Greater Vancouver area.

Contact Rebekah Sandhu, rebekah.sandhu@fraserhealth.ca or (604) 514-6000, ext. 745319.
IFALD, from pg. 1

is examined under the microscope: fat (characteristically an unusual mix of macro- and microsteatosis, or larger and small fat cells), and bile (indicative of cholestasis), which we have called steatocholestasis. A biopsy alone is not diagnostic of IFALD, but it is very useful in helping to determine the diagnosis. Imaging (CT or MR) as well as blood tests are also important in making the diagnosis.

IFALD can be differentiated from NAFLD on the basis of history, biopsy results, and blood tests. Patients with NAFLD are usually obese, have high blood lipids, and don’t require PN; normal plasma free choline and metabolic syndrome are common in NFALD. Those with IFALD obviously require PN.* Their blood lipids are low, as is their plasma free choline; individuals that require long-term PN are rarely obese and have not been reported to develop metabolic syndrome.

Cirrhosis may take ten to twenty years to develop in someone with NAFLD, but may occur in as little as three to five months in patients with intestinal failure. In fact, liver failure may develop in IFALD in the absence of cirrhosis. There are characteristics of the liver tissue that also help differentiate NAFLD from IFALD, although those are beyond the scope of this article.

Within the first two weeks of starting PN, as many as two-thirds of individuals may develop abnormal elevations in their liver tests (not actually “liver function tests,” as the AST, ALT, and alk phos do not reflect the “function” of the liver; function is reflected more by the albumin and bilirubin levels). This often peaks at three to five weeks, but typically these return to normal within one to four weeks of developing nutritional autonomy. The alk phos often becomes more progressively elevated after ten weeks or more. However, it is to be noted that these blood tests are both insensitive and nonspecific indicators of liver disease. In particular, the serum alk phos may reflect biliary disease such as gallstones or sludge and, in children, growing bone.

The serum bilirubin concentration is generally not elevated until the later stages of liver disease, except in pre-term infants, where it is a common initial marker of IFALD. That of course begs the question of whether IFALD in pre-term infants is perhaps just a more severe manifestation of what occurs in older children and adults due to their under-developed biliary systems, or whether the cause is different.

Some studies have shown that as many of 70 percent of adults with intestinal failure may develop IFALD by six years, with over

Abbreviations used:
- AST = aspartate aminotransferase
- ALT = alanine aminotransferase
- alk phos = alkaline phosphatase
- GGT = gamma-glutamyltransferase

*Intestinal failure is defined as “the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth” (ESPEN endorsed recommendations. Definition and classification of intestinal failure in adults. Clinical Nutrition 34(2); 2015).
50 percent developing irreversible liver disease (Cavicchi et al from Paris, 2001). Most centers now report that 15 percent to 30 percent of patients develop IFALD, although the incidence remains much greater in pre-term infants. Liver failure may develop in less than two months in infants that are completely PN-dependent. Why, though, what appears to be a decrease in the incidence of IFALD over the last twenty years in both adults and children? That's unknown, but it may be related to more aggressive attempts at developing nutritional autonomy and weaning PN, earlier recognition and better treatment of catheter sepsis, avoidance of overfeeding and minimizing traditional lipid emulsion, and perhaps other unknown factors.

IFALD Contributing Factors

Numerous factors have been associated with the development of IFALD. These include shorter remaining small bowel, shorter remaining colon, and increased amounts of lipid emulsion (> 1 g/kg/day). In infants, low birthweight/prematurity, the number of surgeries, blood transfusions, and episodes of sepsis are additional risk factors. Duration of PN use has not been consistently uncovered as a risk factor.

Why Choline: The Story of Its Development

My interest in choline was sparked serendipitously when I was working on my master’s degree. I was a full-time fellow, with several “moonlighting” jobs. Chronically short on time, when I had to do two term papers based on material in our Shills and Young nutrition textbook, I picked the two shortest chapters—choline and carnitine.

I learned that choline deficiency results in fatty liver, and growth, memory and hematologic abnormalities in a dozen animal species, from rainbow trout to monkeys. I thought back to a project I had done in 1983 where mice that were made choline deficient developed fatty livers.

Fast forward several years to UCLA, where I saw a lot of patients that required long-term parenteral nutrition at home (HPN) with Dr. Marvin Ament. Many of them had abnormal liver tests and a few that had had imaging done for various reasons also had fatty livers. I wondered, could it be choline deficiency?

There was no commercially available test to measure choline concentrations in these patients. I pored through papers and contacted authors. In a roundabout way, I eventually connected with the world’s choline maven, Dr. Donald Jenden, chief of pharmacology right at UCLA. His lab techs taught me how to measure choline.

We found that the plasma free choline concentration was low in 85 percent of our HPN patients and there was a significant negative correlation between the choline concentration and AST and ALT. I wanted to give the patients choline and see if we could fix their livers, but there was no IV choline.

The oral route had to be used, even though it was not ideal for patients with limited absorption. We settled on liquid lecithin (about 20 percent choline) and an equally disgusting-tasting placebo for our study material. I chose 40 grams in a divided dose daily. That was the largest dose I’d found in the literature given to patients that did not make them throw up.

We found that the lecithin did lead to increased blood choline and improved liver tests, but we could not give enough to make everything normal. We needed an IV form of choline. Based on this work and that of Dr. Steven Zeisel, it was determined that choline was a conditionally essential nutrient for humans.

Enter Ken Breslow, RPh, who helped me desiccate and sterilize choline produced for animals. Because this had not been used in humans I had to get investigative new drug (IND) approval from the FDA. We also needed to determine the right dose and to test how long the choline stayed in the body, what happened to it, etc. Dr. Jenden and Dr. Stephen Fredd, first head of the GI division at the FDA, helped with this. Dr. Fredd helped me design our incremental dose-response study. Based on that study, it appeared 2 g was the most appropriate dose for adults.

I moved to Houston and was able to get a large grant from the FDA to do a real trial. We had our “drug” made by the University of Iowa and did basic testing to make sure it was safe to be put in the PN.

When the study was done, we found that blood choline was easily made normal in patients given the IV choline, and their fatty livers resolved and liver test abnormalities (AST, ALT, and alkaline phosphatase) became normal.

Since then, IV choline has passed through the hands of several small pharmaceutical companies, and some additional research has been done. Today Artara Therapeutics, has taken the lead for manufacturing IV choline. It plans to begin a phase 3 placebo-controlled trial that has been endorsed by the FDA. Hopefully this trial will begin sometime in 2020 and will serve as a model for properly controlled studies of nutrients in PN.

—A. Buchman
Most importantly, we want people on PN to eat! Absorption is a function of not only the percentage of food that you absorb, but how much you take in. One hundred percent absorption, but no oral intake = 0 percent absorption! That's like having no intestine. Individuals should not be receiving so much PN that they are not hungry.

**If You Have IFALD**

What do you do if you have IFALD? There is really no role for repeating liver biopsies because they are potentially risky and once the diagnosis has been made, there is little information to be gained from additional biopsies. Patients should be seen and evaluated in centers with experience in dealing with IFALD, intestinal rehabilitation, and intestinal transplantation; early transplant evaluation does not have to mean early transplant—and shouldn't!

The need for combined liver/small bowel transplants, however, should be avoided. If a small bowel graft fails, the PN option remains. If the liver portion of the transplant fails, “Houston, we have a problem” becomes an understatement.

Can IFALD be treated? No, not really. The FDA has approved fish-oil based lipids (SMOF® in adults, Omegaven® in children; both from Fresenius Kabi, Lake Zurich, IL) as a lipid source in patients with IFALD based on the suggestion that they do not worsen IFALD and therefore may be a preferred lipid source in patients with IFALD. Given there has been no head-to-head, blinded, prospectively controlled trial as is the case for most drugs, the FDA did not feel there was sufficient evidence to suggest that although the bile buildup in the liver (cholestasis) may improve, there is no effect on the liver fat accumulation and IFALD may continue to progress. [Note: the clinician reviewer comments, “Most pediatric gastroenterologists involved in intestinal rehabilitation believe Omegaven is one of the factors that has decreased the need for liver transplants.”]

Although some patients are given carnitine in their PN, studies from as far back as 1986 have shown that carnitine was unable to treat IFALD. There really is no reason for it to be given. Carnitine concentrations in the blood are often about 50 percent of normal during PN, but nowhere near what is needed for carnitine deficiency to develop.

Ursodeoxycholic acid has been used in infants with IFALD with varying degrees of success. There is only a single case report of successful use of ursodeoxycholic acid in an adult patient, though anecdotally it has been used in many adults.

In those individuals with IFALD, it is probably prudent to avoid alcohol. In fact, a French study found outcome was worse in patients that have IFALD and drink alcohol.

**New Research: Choline**

Choline (the major component of lecithin) is part of all cell membranes. Normally, it is made in the liver from methionine, one of the amino acids supplied in PN. However, studies from the 1970s showed that when methionine (and quite possibly the other amino acids) is infused through a vein, into the heart, it bypasses the normal process by which nutrients that are eaten would be metabolized in the liver. As such, methionine concentrations in the blood of those on PN are often at the upper level of normal or even elevated, because the methionine is not fully metabolized.

When methionine is metabolized in the liver, one of the products that results is choline. Two studies have suggested that about 80 percent to 85 percent of individuals that receive long-term PN have low plasma free choline. Studies in animals have shown that IFALD developed when there was no choline in the PN; IFALD was even more severe when the choline-deficient animals were infected. Animal studies have also shown that giving choline in PN eliminates the fat in the liver that occurs during PN and not eating and also increases the flow of bile; severe liver disease that occurred in choline-deficient and infected animals did not occur when animals that received choline were also infected. Liver cells also die when they don't have enough choline, even when there is no infection. Small, but placebo-controlled human studies have also shown choline eliminates the extra fat in the liver that occurs during PN and reduces cholestasis. A larger, placebo-controlled trial of choline (ArTara Therapeutics, New York, NY) to treat IFALD in older children and adults is anticipated and should show whether it is an effective treatment or not.

In conclusion, IFALD is a common and potentially very serious complication of malabsorption/intestinal failure. We are getting better at predicting it and understanding why it develops. Effective treatment other than transplant has been elusive, but as our overall knowledge and experience with helping patients that require HPN grows, the incidence seems to have decreased. Investigational therapies hold tremendous potential for treatment, but we need to see what the future holds.

The author reports a minor (0.25%) stock ownership in ArTara Therapeutics, which is developing intravenous choline chloride as a treatment for IFALD.

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**Silent Auction Items Needed**

Make the 2020 Oley conference silent auction stupendous! Donate popular items such as: small electronics, jewelry, handmade pieces, gift certificates and toys/games. Consider items specific to your hometown!

We are also taking donations for themed baskets: dog, cat, vacation/summertime, kid activities, date night, relaxation/spa, and sports. Bring an item for the basket or team up with others to sponsor a basket! Bring contributions to the annual conference (see page 1) or email marywooten. oley@gmail.com to make shipping arrangements.
From the Desk of Joan Bishop, Executive Director

As we ended one year feeling grateful and look forward to the promises of another, we are reminded of our important mission, “Striving to enhance the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.” We recognize that we are successful because of the community that surrounds us. We have a fantastic Board of Directors and a strong Advisory Council to guide us. We enjoy the support of over 55 Oley Ambassadors who are the faces of Oley in their communities. So many members are quick to respond favorably to help, whether to respond to others who are in need of support or guidance, to participate in market research projects, etc.

We are committed to keeping the Oley Foundation the trusted source of information. Whether you attend a meeting or a webinar, watch a video, visit www.oley.org, call or write, we want you to feel comfortable approaching us and satisfied when you leave. This is your organization!

We also acknowledge that we couldn’t stay forward-thinking without financial support. The Corporate Donor list (on page 15) showcases companies that seriously recognize the importance of our work and your need for information, support, and hope. They believe in and invest in YOU! The list of individual donors is also impressive in 2019. We thank each and every donor including those who have arranged for a planned gift. We are grateful to be a part of your life. We hope that you find 2020 a year that is as rewarding and meaningful as possible.
Advance Directives, from pg. 1

a feeding tube inserted as a death-delaying procedure at the end of their life, but I have to decide when to stop using my tube, and then I have to communicate my wishes to family members, friends, caregivers, and doctors. Since I’ve been totally dependent on my tube for all of my nutrition, hydration, and medications for more than fourteen years—absolutely nothing by mouth, or I end up in the hospital with aspiration pneumonia—this would be tantamount to, well, starving myself to death.

Under what conditions would I want to do that, and what type of documentation do I need to have in place if I’m unable to express my wishes? This presents a whole slew of legal, logistical, medical, moral, and existential issues that must be addressed now, while I’m still healthy and of sound mind; otherwise, some distraught relative or overzealous doctor might interfere with my wishes and prolong a life I may no longer want to live. It all boils down to what to do, how much to do, and when to stop.

I’ve been studying these weighty and controversial questions and I’d like to share what I’ve learned, but first, a major caveat: I am not a doctor or a lawyer, and I am not offering advice or suggesting you follow my lead. Whatever you do, seek legal guidance to make sure you’re adhering to state and federal requirements, and discuss your wishes with your doctor and your loved ones now—before it’s too late.

Advance Directives and Tube Feeding

An advance medical directive is the basic building block for addressing these issues; it consists of a living will, in which you spell out what kind of care you want and don’t want, and a medical durable power of attorney, in which you appoint someone who will speak for you when you can no longer speak for yourself. The forms to use differ from state to state, so be sure to check out a reputable website such as www.aarp.org/advancedirectives or consult with an estate planning lawyer for the documents your state requires. It all seems pretty straightforward, but for those of us with tubes, it’s not.

I live in Illinois. The Illinois statutory short form power of attorney for health care (sorry for all of this legal gobbledygook), the form I have to use to appoint someone to make medical decisions for me when I am incapacitated, includes life-sustaining interventions such as cardiopulmonary resuscitation (CPR) and breathing machines. But it also includes “tube feedings or fluids through a tube” as a life-sustaining treatment, and this is the crux of the problem for those of us who are dependent on enteral and parenteral nutrition: These forms are asking us whether we want a tube inserted to sustain or prolong life, not whether we want to stop using our tubes that we can’t live without. That means I have to define the circumstances under which I would not want any more nutrition, hydration, or medications through my tube, but none of the standard forms address that unique situation.

It is important to state that the voluntary stopping of eating and drinking (VSED) is a legally established concept and right, but only for those competent enough to make such a decision; that is why it’s so important to make your wishes known now, so that no one can challenge your decisions later if you start slipping away. Interestingly, Cruzan v. Director, Missouri Department of Health, the first right-to-die case heard by the U.S. Supreme Court back in 1989, involved the removal of a feeding tube.

Making My Decisions

In my search for guidance, I’ve located three tools that have helped me define how I want to die: The 6-Steps Living Will, Five Wishes, and My End-of-Life Decisions [see sidebar for contact information]. I have combined elements from all three documents in my planning.

First, I defined the circumstances under which I’d no longer wish to live. For example, if I were to suffer a traumatic brain injury or a massive stroke and end up in a permanent vegetative state or with locked-in syndrome, or if I am in an advanced stage of a terminal illness, including dementia, and at least two of my doctors do not believe I will recover, then I would not want any of the death-delaying procedures outlined in table 1 (see page 9). I compiled this list based on extensive reading, on the three tools referenced above, and on my personal experience.

In these circumstances, I opt for “comfort care only,” including the administration of medications through an IV or through my feeding tube to alleviate pain and anxiety, an oxygen mask or nasal cannula to assist with breathlessness, and oral suctioning of mucus and saliva that may pool in my mouth and throat. I do not want to receive nutrition or hydration through my feeding tube. On a personal note, I am allergic to Compazine (prochlorperazine), so I have indicated that under no circumstances is this to be used to control nausea or vomiting.

I’ve discovered another wrinkle in my planning: Because I am currently in an HMO, I am limited to the network of hospitals where I can be treated and admitted. This particular network’s mission is “inspired by the healing ministry of Jesus Christ,” so I am not sure if my end-of-life wishes and decisions would be honored. As such, I’ve signed a sectarian healthcare directive—included in the My End-of-Life Decisions booklet mentioned above—requesting to be transferred to a hospital that would honor my wishes. But there’s a catch-22: Any hospital that I transfer to would be out-of-network, and so wouldn’t be covered under my current insurance plan. I’m hoping that nothing happens before my next birthday, because after that I qualify for Medicare and can go anywhere I want.
Important Details
As you can tell, I’ve given this quite a lot of thought. There are other things, not included in the typical advance directives, that are
important to me (see below). I’ve included these as part of the Five Wishes document. All of it has been signed by myself, my lawyer, and
a witness, and has been notarized.
I have discussed all of these wishes with my sisters and nephews,
and my primary care doctor, and I have given them copies of all of
the important documents. My lawyer also has copies. Everything is
neatly arranged in a three-ring black binder next to my desk.

Additional Considerations
Here are some of the things I’ve added to the Five Wishes document.
I prefer to die in hospice, not in a nursing home and definitely
not in a hospital. Although hospice care typically does not include
the placement of feeding tubes, I checked with three local hospice
organizations in Chicago and they all told me they would never ask
someone who already had a feeding tube to remove it in order to be
eligible for hospice care.
During my final days, I would like to listen to WFMT’s calm and
soothing classical music (but not opera). I do not like the sounds of tele-
vision, especially commercials, so please don’t place me near one unless
I specifically ask to watch one of my favorite programs, like Jeopardy.
I have a heightened sense of smell; for the most part, I enjoy the smells
of food, but I’m never sure what might trigger an adverse response, so
please limit any cooking in my immediate area, if possible.

Table 1. Personalized list of life-sustaining procedures
(developed by the author)

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<th>Procedure</th>
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<td>CPR</td>
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<td>Electroshock to stimulate heart</td>
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<td>Medications to stimulate heart</td>
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<td>Mechanical ventilation/respiration</td>
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<td>Breathing tubes inserted in mouth, nose, neck</td>
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<td>Nasogastric tube</td>
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<td>Dialysis</td>
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<td>Surgery, especially to my neck and throat area</td>
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<td>Blood transfusions</td>
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<td>Chemotherapy/Radiation</td>
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<td>Antibiotics to fight a life-threatening infection</td>
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<td>Corticosteroids, especially prednisone, on a long-term basis</td>
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<td>Nutrition through a feeding tube</td>
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<td>Hydration through an IV</td>
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I particularly enjoy the soothing and calming scent of lavender, and
the Meyer’s brand of candles.
I crave light and sunshine and fresh air, so if possible, please place
me near a window; I like to sleep with my socks on.
I am very claustrophobic, so please do not ever cover my face or lean
over me in such a way that triggers an involuntary violent response.
Do not ever put me in restraints.
Until I stop eating through my tube, remember that I need to be sitting
up when I feed and for at least two to three hours afterwards; otherwise,
the formula may come up and go right back down into my lungs.
Please dab my lips with a moist washcloth and periodically apply
Kiehl’s lip balm.
Since radiation has destroyed my salivary glands, I often wake up in
the middle of the night because my mouth is so parched that I have to
get up and swish cold water around and spit it out. When I’m unable
to do that anymore, perhaps swabbing my tongue and mouth with a
damp washcloth will help.
I am very concerned about the proper care and maintenance of my
feeding tube. Nobody will ever take care of my tube the way I do.
Lastly, I don’t want a traditional religious memorial service in a
funeral home or at a cemetery. Instead, I’ve set aside funds for a party
to be catered by a Jewish deli like Manny’s in Chicago or Zabar’s in
New York. Please order all of my favorite foods, like freshly baked
bagels, smoked white fish, lox, nova, Philadelphia cream cheese,
chopped liver, matzo ball soup, corned beef, pastrami, brisket of beef,
rye bread, challah, and Dr. Brown’s soda. Be sure to load up on tons
of delicacies from the bakery. BYOB. Play my favorite music, read
my favorite poems and excerpts from my books, look through all of
my photo albums, dance and have a wild time, and then spread my
ashes over the Atlantic or the Pacific or in the Mediterranean Sea off
the coast of Israel. ¶
Thank You for Your Support in Fiscal Year 2019!

The following list represents everyone who contributed toward Oley’s efforts in our 2019 fiscal year: October 1, 2018, to September 30, 2019. Donated 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, 2019, or later will be acknowledged in next year’s listing.

Generous Gifts Without Bounds ($5,000+)

Steven Atkinson, includes matching gift from Johnson & Johnson
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Nancy, Peter, Jerry, and Alana Kudan, in memory of Shirley Klein, beloved mother, mother-in-law and grandmother who passed away 20 years ago after having been on HPN for 20 years
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We also want to thank those who are not listed below, yet have suppliant, we’ve created a separate list, which can be found on pages 13–15.

Harlan Johnson
Daniel Kamin
Sue Karacki, in memory of Larry Karacki
Jill and Jake Krautkremer
Vanessa Kumpf, PharmD, BCNSP
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Jennifer Thiesse**, in memory of Ruth and Roland Milow, Kathy Bucher, and Jennifer’s dad

Donors, cont. pg. 12

Special Shout Outs
People who supported the Oley Foundation in FY2019

• with in-kind gifts: Timothy Arends/Dorsey & Whitney LLP; Cardinal Health; Coram / CVS specialty infusion services; MagicWig Productions, Inc.; MOOG Medical

• through purchasing at AmazonSmile,

• via Facebook, including campaigns by: Heidi Robertson Andolina; Dianne Archer; Shirley Au; Hadar Birger-Bray; Robin King Bodnar; Betty Bond; Michelle Barford; Abby Carpenter; Roslyn Dahl; Tiffany Dodd; Jacquelynn Gibson; Katie Hatcher; Cathy Hotaling Harrington; Carrie Baker Muir; Malik Kaume-Dau Saunders; Delores Salvinski; Naemah Seals; Teri Williamson; Pam Winter; Jim Wittmann; Lynn Nagin Wolfson, and…

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Donors, cont. pg. 14 ☛
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 9, 2019, to January 24, 2020.

Tributes: In honor of all warriors and caregivers; Julie Andolina; Daniel Appel and Rebecca Appel; Cody Bakkila; David Benda; Dan Benshoof; Hadar Birgener-Bray; Joan Bishop; Bettemarie Bond and family; Lynda Bosworth, “a true inspiration with her positive outlook”; Sally and Bill Bowers; Sarah Bowers and the Bowers/Stickney family; Roslyn Dahl; Rick Davis; Jackson Merrill Dietel; Susan Friedman, “being there 24/7”; Todd and Susan Friedman; Derick Goldsmith, 2019 recipient of the Kyle Noble Memorial Scholarship and an inspiration to many; Lynn Marie Gregor; Lyn Howard; HPEN consumers and families; Ed Kellerman; Phil Kellerman; Aidan Koncicus; Kody Limbrunner, fifteen years on tube feeds; Al Mackay’s hike; John Mahalchak; Jennifer Mason; Larry and Carol Mayer; Michael Medwar and family; “my colleagues, working hard every day to educate clinicians and better the lives of patients on parenteral nutrition”; Natalie Rosenthal; Stephanie Salerno; thirty years on HPN; Cathy Tokarz

Memorials: In memory of Michael Aklufi; all the people who died this year; Nancy Backinger; Gisela Barnadas; Michael Baumgartner; Pat Brown; Lori Ann Campbell; Ann DeBarbieri; Clifton Dodge; Charlie Eitem; Donald Engle; Irmagail Gordon; Theresa Grasso; Richard M. Harris; Arthur and Marjorie Hashbarger; Zoe Allison Caulder Hartley; Marilyn Huhner; Alisha Hoelle; Joyce Hydorn; Nina L. Irton; Pamela Jenkins; Larry Karamb; the Klein family; Martin Koenig, “the smartest, funniest guy we’ve met”; Robin “Peaches” Lang; Julie Walker McAnally; Peter Joseph Michalski; Kevin Murphy; Francis J. Murray; Larry Karacki; Sarah Kopp; Michael Medwar and family; “my colleagues, working hard every day to educate clinicians and better the lives of patients on parenteral nutrition”; Natalie Rosenthal; Stephanie Salerno; thirty years on HPN; Cathy Tokarz

Fund-raisers: Amazon Smile; Facebook Birthday Fund-raisers: Lhoidz Amores, Tiffany Dodd, Candace J. Jackson, Ally Winter, Jim Wittman; Facebook Fund-raiser: Heidi Andolina; Real Food Blends’ 12 Days of Holiday Magic campaign

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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.

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Boscov’s gift-wrapping event  
BriovaRx Infusion Services booth fund-raiser at ASPEN’s annual conference  
Phil Kellerman’s Rotary Club music event and CD sales  
Phil Kellerman’s ongoing political memorabilia fund-raiser on eBay  
Al Mackay’s Long Trail hike  
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Shire, now part of Takeda Pharmaceutical, booth fund-raiser at Digestive Disease Week

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2020 Oley Calendar

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

March 1–2: Oley participating in Digestive Disease National Coalition (DDNC), Washington, DC

March 5 (and then the first Thursday every month): Philadelphia Suburbs Tube Feeding/HPN Support Group, Blue Bell, PA, more info @ www.oley.org/SupportGroups

March 17 (and then the third Tuesday every month, August through May): South Florida Ostomy and Tube Feeding/HPN Support Group, Weston, FL, more info @ www.oley.org/SupportGroups

March 20: Nominations for Oley awards, applications for Kyle Noble Scholarship, and submissions for HPN Research Prize due

March 28–31: Oley exhibiting at and attending the ASPEN Nutrition Science and Practice Conference, Tampa, FL

April 5–9: Oley attending National Home Infusion Association (NHIA), Aurora, CO

April 25 (tentative): Oley Regional Conference, Charlotte, NC

May 2–5: Oley attending and participating in Digestive Disease Week, Chicago, IL

May 11–14: Oley exhibiting at American Pediatric Surgical Nurses Association (APSNA) Scientific Conference, Orlando, FL

June 21–23: Oley 2020 Conference, Newport Beach, CA

September 9–12: Oley attending and exhibiting at AVA 2020 (Association for Vascular Access), Denver, CO

October 12–16: HPN Awareness Week


For updates or if you are able to help at one of the Oley exhibits listed above, please email harrinc@amc.edu or call (518) 262-5079.

Additional Meetings of Interest

March 13–15: American College of Gastroenterology (ACG/FGS) Spring Symposium, Naples, FL

May 16–19: Infusion Nurses Society (INS), Las Vegas, NV

May 30–June 2: American Society of Nutrition (ASN), Seattle, WA

June 17–19: World Congress on Vascular Access (WoCoVA), Athens, Greece

June 24–27: Mitochondrial Medicine 2020 (UMDF), Phoenix, AZ

June 26–28: International Pediatric Intestinal Failure Rehabilitation Symposium, Ontario, Canada