Why Are Clinical Trials Important?

Robert L. Ferris, MD, PhD

Clinical trials are a key research tool for advancing medical knowledge and patient care. Clinical research is done only if doctors do not know whether a new approach works well in people and is safe, and which treatments or strategies work best for certain illnesses or groups of people.

Clinical trials are important for discovering new treatments for diseases, as well as new ways to detect, diagnose, and reduce the chance of developing the disease. Clinical trials can show researchers what does and doesn't work in humans that cannot be learned in the laboratory or in animals. Clinical trials also help doctors decide if the side effects of a new treatment are acceptable when weighed against the potential benefits. Researchers don't know what the results of clinical trials will be. (If they did, they wouldn't have to do the trials!) This uncertainty can make it hard for a patient to decide to participate in a clinical trial. While in rare cases, patient volunteers have been hurt by the treatment or procedure on a clinical trial, millions of people have been helped because other people before them chose to participate in a trial that resulted in a new, more effective treatment.

While clinical trials are important, the choice to participate in one is very personal and depends on your unique situation. You and your doctor need to weigh...
Clinical Trials, from pg. 1

the benefits against the risks and decide what's best for you, when presented with a clinical trial. According to the American Cancer Society, about 1,000 potential medicines are tested before one makes it to clinical trials. On average, new cancer treatments have been studied for at least six years (and sometimes many more) before a clinical trial is started. Usually by the time a treatment makes it to the stage of a clinical trial, it has been found to be safe and to have some chance of being effective. In some cases, a treatment is safe and already FDA-approved and standard practice in one disease, and the clinical trial is testing it in another type of disease.

How Clinical Trials Work

If you take part in a clinical trial, you may get tests or treatments in a hospital, clinic, or doctor's office.

In some ways, taking part in a clinical trial is different from having regular care from your own doctor. For example, you may have more tests and medical exams than you would otherwise.

The purpose of clinical trials is research, so the studies follow strict scientific standards. These standards protect patients and help produce reliable study results.

Clinical Trial Protocol

Each clinical trial has a master plan called a protocol, which explains how the trial will work. The trial is led by a principal investigator (PI), who usually is a doctor. The PI prepares the protocol for the clinical trial.

The protocol outlines what will be done during the clinical trial and why. Each medical center that does the study uses the same protocol, which is reviewed and approved by various committees. The committees are in place to ensure patient protections and some potential of learning new information or benefitting patients with the disease.

Key information in a protocol includes how many patients will take part in the clinical trial; who is eligible to take part in the clinical trial; what tests patients will get and how often they will get them; what type of data will be collected during the clinical trial; and detailed information about the treatment plan.

The researchers doing clinical trials take steps to avoid bias. “Bias” means that human choices or other factors not related to the protocol affect the trial’s results.

Comparison Groups

In most clinical trials, researchers use comparison groups. This means the patients taking part in a trial are assigned to one of two or more similar groups. Each group will receive different medical strategies. For example, one group may get the current standard treatment for a condition, while another group gets a new treatment. Researchers can then compare the results to see whether one group has better outcomes than the other.

Using comparison groups also ensures that no one in a study is left without treatment for the sake of research. Sometimes, when no accepted standard treatment exists for a condition, people in one group may receive a placebo (inactive pill that looks like the test product). You’ll be told if a placebo will be used in a study before you agree to take part.

Randomization

Some clinical trials that have comparison groups use randomization. This involves assigning patients to different comparison groups by chance, rather than choice. This method helps ensure that any differences observed during a trial are due to the different strategies being used, not to preexisting differences between the patients. Usually a computer program makes the group assignments.

Possible Benefits and Risks of Clinical Trials

Taking part in a clinical trial can have many benefits. For example, you may gain access to new treatments before they’re widely available. If a new treatment is proven to work and you’re in the group getting it, you might be among the first to benefit. If you’re in a clinical trial and don’t get the new strategy being tested, you may receive the current standard care for your condition. This treatment might be as good as, or better than, the new approach. You also will have the support of a team of health care providers, who will likely monitor your health closely.

Clinical Trials, cont. pg. 12
**Tube Talk**

Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@mail.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.

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**ENFit® Update**

The Oley Foundation was founded over thirty years ago to serve home enteral and parenteral nutrition (HEN and HPN) consumers. The safety and well-being of nutrition support consumers is in the forefront of all that we do. Today, changes seen in the enteral market—specifically, the introduction of International Organization for Standardization (ISO) standard 80369-3 and new enteral tubing connectors known as ENFit®—have the potential to affect both HEN and HPN consumers. And while HEN consumers are having a mixed reaction to the change, both HEN and HPN consumers may benefit as the risk of tubing misconnections will be reduced and patient safety increased.

Oley is aware of several concerns surrounding ISO 80369-3 and ENFit, and remains committed to facilitating an open dialogue between consumers, members of industry, the Food and Drug Administration (FDA) and the clinical community, and working towards seeing these issues resolved. We also applauded the effort to reduce tubing misconnections, which is the stated goal behind this initiative.

**Syringes**

ENFit tip syringes are available by prescription, and as such should be covered by insurance. They must be obtained from either a licensed pharmacy that provides your medication or the company that provides your enteral nutrition. Retail pharmacies should provide ENFit tip syringes when they provide medication to be administered via a feeding tube with an ENFit connector. It might be worth a call to make sure your pharmacy knows you will be giving the medication through a feeding tube, and to be sure they stock the syringes you will need. At this time, ENFit tip syringes are not considered over-the-counter devices, and therefore they cannot be ordered online or purchased at local pharmacies.

Oley remains committed to the issues that impact you, including reimbursement and availability, and is part of a working group to discuss both of these issues in regard to ENFit tip syringes.

**“Legacy” Tubes**

We are also being told by manufacturers that the current “legacy” feeding tubes, without ENFit connectors, will remain available indefinitely. Mayo Clinic in Rochester, Minnesota, and the FDA have been researching the flow rates and force required to administer different commercial and homemade formulas through the legacy and ENFit tubes, and hope to publish the results of those studies some time this summer. We look forward to sharing the results with you.

**From the FDA:** “While the FDA encourages manufacturers to incorporate the new connector design standards for enteral devices and other future device types, the [FDA] is not requiring manufacturers to switch to the new standard design, or to remove products currently in use from the market. Devices with older designs (legacy devices) may still be available on the market for patients who rely on them for their care.”

To read more from the FDA go to: https://www.fda.gov/MedicalDevices/Safety/AlertsandNotices/TubingandLuerMisconnections/ucm313267.htm

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We know some of our members are concerned about the new connectors, fearing they may impact their ability to use a blended diet, to administer formula quickly, or lead to other problems. Others are excited about the new connectors, because they cannot interconnect with an IV line and are less likely to come apart (once the adapters are out of the picture). If you have experiences with the ENFit connectors—positive or negative—please share them with us at (518) 262-5079 or metzgel@mail.amc.edu.

For further information regarding ENFit, including frequently asked questions, visit www.stayconnected.org. There is also information on the Oley website at oley.org/page/enfitconnectors.

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Natalie and her mom, Mary (an Oley Ambassador), helped Natalie’s classmates understand tube feeding better.

**Feeding Tube Awareness Week 2017**

Thank you to Oley members who shared their stories, photos, concerns, and successes during Feeding Tube Awareness Week. We distributed 1,350+ buttons, our video was viewed 1,000+ times on You Tube, 75+ people joined us for our “Notes from a Plumber’s Helper: Clogs I Have Known (in Feeding Tubes)” webinar, and several people shared their stories with their local newspapers. And we know there were hundreds of other efforts—from social media posts to school presentations (see above)—during the week.

You can catch the video and the webinar on the Oley Foundation You Tube channel (youtube.com/TheOleyFoundation), and find links to the stories at www.oley.org/page/FT_Awareness_Week. Let us know if you’ve got a Feeding Tube Awareness story to share, and we’ll add it to our website!

Join us for HPN Awareness Week, August 7–11, 2017. Send your photos now for the video to metzgel@mail.amc.edu.

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My name is Brian McCall. I’m fifty-five years old, and I’m from Long Island, New York. My tale, as it relates to Oley, began in August 2005, when I took my family on a tour of Pennsylvania. We were going to visit a couple of amusement parks and had planned on stopping by a couple of companies that my company does business with.

The Ride Begins
It was a wonderful trip. My daughter and I rode the big roller coasters and I got to meet several business colleagues. On the last day of our trip, I didn’t feel right when I awoke, but I drove home according to plan. Late in the afternoon, after unpacking, I really felt bad. I was over shape and out of weight (reverse that), so I thought I might be having a heart attack. I went to take aspirin.

Behold and lo, I could not swallow the tablets nor the water. It was off to the emergency room. After a night in the ER, it was determined I had had a stroke. They transferred me to a hospital in New York City for treatment. I had a procedure done, aspirated a few hours later, and was intubated and moved to a neuro intensive care unit.

After a couple of days, I had a feeding tube placed. I really thought nothing of it. I just wanted to get out of the hospital. With a hole in my throat for a trach and a tube sticking out of my stomach, I was transferred back to my local hospital, where I spent four more weeks going through physical, occupational, and speech therapy. The neurologist said my stroke was probably caused by whip splash from a roller coaster ride. Imagine that. I had so much fun I had a stroke!

Downs and Ups, Ups and Downs
I was discharged and sent home. Because I was put on Coumadin, a nurse came to my house once a week to check my levels. The doc adjusted my dosage accordingly. I attended outpatient therapy three times a week. The emphasis was on getting to walk again, and the speech therapist concentrated on therapy to get my swallow back.

The feeding tube was sort of “just there.” I hadn’t been given any tube care guidelines or anything. Sound familiar? My speech therapist had mentioned the Oley Foundation to me while I was in hospital, but I didn’t pursue anything at that time.

Anyway, for several months after my stroke, I was lucky if I put in 750 calories a day, and I lost about 120 pounds. My primary care doctor told me enough was enough, that I needed to get more calories and more water into me. I got on with developing my tube feeding routine. I upped my intake from three cans a day to about eight, and added more water.

My first tube was a long, dangling tube with a mushroom-type bolster. I was told I would have to go a doctor to have it changed, and that I would need to be under anesthesia when the tube was removed. That was of no particular interest me, so I kept putting it off. That first tube had a heavy y-port, with a toll-free number on the side. After the caps got brittle and worn out, I called the number looking for a replacement port.

The company told me they could not sell to the end user, and they did not offer any suggestions, except for me to contact my supply company. Well, I did not have a supply company, so I purchased a couple replacement ports off the internet. The ports have barbed fittings to push into the tube, so changing them was difficult. I would just cut the tube below the port and push in a new one. I did this several times, until my dangling tube got to be this little stub of tube sticking out. (See note at end of article on page 5)* It was time for a change. The doc I went to said he would place a tube with a balloon-style bolster, and future changes could be done in his office, with no need for the anesthesia.

During that time, my sister who lives in Salt Lake City, Utah, said the Oley conference was being held there, and Rick Davis, who was an associate of my brother-law’s, was going to be there. Like me, Rick had had a stroke that knocked out the ability to swallow. My sister went to the conference for a day and told me all about it. That’s when I really started looking into Oley for support. I discovered they held an annual conference in places all over the country. I wanted to go.

I work for a swimming pool company here in New York, and the conference dates were always the week before the Fourth of July. Not a good time for me to take off. Conferences were held in Saratoga Springs, New York, and Cape Cod, Massachusetts—both within easy driving distance for me—but the timing was bad. I would check out the photos from the conferences and kick myself for not going.

Exciting Twists and Turns
To my supreme delight, the dates for the 2016 conference were July 5–July 9. I could go! The 2016 conference was being held across the country in Newport Beach, California, but I was determined to attend. I made plans to bookend the conference with a visit to my sister in Salt Lake. I booked my journey. Of course, nothing was direct. I was on eight planes in eight days.

I flew into Salt Lake on Monday July Fourth, and headed to Newport on Tuesday the fifth. I kept thinking of the line at the end of the movie The Shawshank Redemption, when Morgan Freeman says, “I’m so excited, I can barely sit still or hold a thought in my head.” That was for sure. I had never seen the Pacific, and I was hoping to maybe get a chance to dip my toes in someday.

On the cab ride from the airport I stopped at the supermarket to get a case of water, and then it was onward to the Marriott. Not only had I not seen the Pacific, but I had never been to California. All the sights were wonderful and new.

I got myself situated and then I went to the welcome reception which was being held outdoors. I immediately met some acquaintances. However, I had only packed shorts and short-sleeve shirts.
(it was Southern California in July after all), and it got chilly once the sun set. I didn't stay for the entire party. The next day was seminar day, with a variety of topics, all of which I found fascinating. Then the exhibits and lunch began. I went back to my room and retrieved the Sanford Stand I had gotten from Master Chief Flach, got back to the exhibit hall, and sat at a table and poured in lunch. It was my first time ever feeding in public. I know some Oley members don't have a problem with that. I'm just not able to overcome my modesty. But it was all very "normal" while in that big ballroom. I got to meet and talk to several exhibitors and other Oley members. I met members that had testified in Congress, and when I got back to New York, I wrote the first letters I had ever written to my congressman. It was such a feeling of community. That night, I went across the street to the big mall to buy an extra bag to carry all the goodies I had picked up.

The second day, I attended the morning seminars, and sat with Dr. Lyn Howard (an Oley Foundation co-founder). We chatted like good friends. She is a truly amazing lady. One of the morning presentations was called "To Swim or Not to Swim." I was particularly interested in this topic, because I love swimming in my own pool and, being in the business, I was very interested as to what the medical field had to say about swimming. I had read about swimming with tubes on the Oley site, but this was firsthand information. My ignorance arose when folks talked about "central lines" for parenteral (IV) nutrition. I have no concept or experience with such lines. I just know the tube into my stomach. I attended the breakout session in the afternoon about swimming to add my two cents of knowledge regarding swimming pool sanitation. I felt that I contributed a little, which is a pretty rewarding feeling. Then it was off to the airport and two planes back to Salt Lake. I spent a few days in Salt Lake doing the tourist thing, and then two planes back to Long Island. I never did get the chance to get my tootsies in the Pacific.

Back Home
When I got home, I had the time to process my experience. I thought it was absolutely wonderful. One of the things that had been on my mind before the conference was the new ENFit® connectors that are being discussed for feeding tubes. Talking with the feeding tube manufacturers in the exhibit hall, who assured me they will still manufacture the current, "legacy" tubes, was very comforting. I have a Mic-Key button, and I like the catheter-end extension tube.

I was delighted to hear that the 2017 conference will be held after the Fourth of July, and it's in Old Greenwich, Connecticut. I know some folks had long, long drives to past conferences, but Greenwich is really sort of in my backyard. I look forward to hearing from and meeting some amazing people again that are doing wonderful work. I don't think anyone wants life support from a tube, but thank goodness for the tremendous support the Oley Foundation offers. Help along way. Perfect. See you in Greenwich!

*Editor's Note: The Oley Foundation does not sanction the practice Brian describes on page 4, and cautions against buying tube parts from unknown sources off the internet. As Brian would agree, it is always important to get proper information and support.
Repeal and Replace, Health Care Reform, Affordable Care Act—How Will Your Care Be Affected?

Lisa Metzger

In early March, about 150 health care consumers and health care providers, along with representatives from patient advocacy organizations, professional societies, and industry, met in Washington, D.C., for the annual Spring Public Policy Forum organized by the Digestive Disease National Coalition (DDNC), which the Oley Foundation is part of. The DDNC’s stated mission is to work cooperatively to improve access to and the quality of digestive disease health care in order to promote the best possible medical outcome and quality of life for current and future patients. To do this, and to increase public awareness of digestive diseases, DDNC coordinates one or two public policy forums annually.

Repeal and Replace

On the first day of the spring forum, the group was provided with details on some of the key policy issues of interest to our community. The second day of the forum, we formed groups according to which state we were from, then went to the Senate and House buildings to visit legislators’ offices. The DDNC had coordinated half-hour meetings with the staff of nearly one hundred Senators and Representatives. The most important part of each of those meetings was the patient’s/consumer’s story. Legislators want to know how health care legislation affects their constituents.

High on the list of key policy issues was health care reform, or “repeal and replace” of the Affordable Care Act (ACA). Whatever happens with health care legislation in the next few months, we feel it is critical to our members that certain basic patient protections of the ACA are included in any new health care plan. This idea is supported by the emails you have sent us about your experiences and concerns (thank you for sharing!).

The basic protections DDNC and the Oley Foundation are focused on at this time include:

- Prohibition of pre-existing condition discrimination;
- Prohibition of lifetime and annual caps on insurance benefits;
- Limits on out-of-pocket costs for patients; and
- Allowing young adults to remain on family health coverage until age twenty-six.

Keeping You Informed

The new American Health Care Act (AHCA) was introduced as a replacement to the ACA (also called “Obamacare”) the same week as the Public Policy Forum. As things change daily in regards to health care reform, it doesn’t make sense to comment extensively on the AHCA here. Suffice it to say that while the legislation includes provisions that address the four basic protections cited above (with a clause that insurance companies can charge a penalty to anyone—not just those with pre-existing conditions—who has a gap in coverage for more than sixty-three days), the bill is facing a great deal of opposition for a number of reasons—as I’m sure you will have read elsewhere.

As we get updates on health care reform/repeal and replace/the ACA and AHCA, as well as other legislative issues relevant to our members—from the DDNC, the National Organization for Rare Diseases (NORD), and other reliable sources—we will post them to the advocacy page on our website. Information on how to contact your elected officials and sample letters are also available. See www.oley.org/Legislation.

Be at the Table

Apparently, a common saying in Washington is, “If you’re not at the table, you may be on the menu.” It is an important time for you to be at the table. Make your voice heard. Participate as you are able. If you can’t attend the forum (and it is a busy two days!), write a letter or email, or call your legislator’s office. Share your story or concern with us (metzgel@mail.amc.edu); if you don’t want to contact your legislators directly, we can pass along your experiences.

Equipment-Supply Exchange

Do you have supplies and formula you no longer need? Or do you have needs that aren’t covered by insurance? Try the Oley Foundation’s Equipment-Supply Exchange.

- Items are available free of charge, but the person requesting supplies must pay for, and arrange for, the items to be shipped to them.

Go to oley.org/Equipment_Exchange to request items through Oley’s online store, send information on donated items via an online form, or find out more about the program. If you don’t have access to the internet, call toll-free (866) 454-7351.

Please be patient. It may take a few days to return a call or answer a request. Typically there is a two-week turnaround from when your request is made until items are received—when the items are available.
Board Spotlights

Manpreet Mundi, MD, and Beth Gore, PhD, MBA, are two of several who joined the Oley Foundation Board of Trustees last year. We are pleased to welcome them. Watch future issues of the newsletter for bios of the other new members.

Manpreet Mundi, MD

Dr. Mundi graduated cum laude from the University of California, San Diego, with a double major in psychology and chemistry. He obtained a degree of Medical Doctor from the Keck School of Medicine at the University of Southern California. Dr. Mundi completed a residency program in internal medicine followed by a fellowship in endocrinology at the Los Angeles County–University of Southern California Medical Center.

After completing his fellowship, Dr. Mundi joined the Mayo Clinic Division of Endocrinology as an NIH training grant fellow in Dr. Michael Jensen’s lab with a research focus in fatty acid metabolism and obesity. Dr. Mundi subsequently joined the clinical staff at Mayo Clinic as a consultant in the Division of Endocrinology nutrition core group. His clinical focus is on obesity and malnutrition with a special interest in home and inpatient nutrition support.

Dr. Mundi is currently an Associate Professor of Medicine and holds the leadership positions of Community Core group chair and Outpatient Nutrition Core group chair. He is also the medical director of the Home Enteral Nutrition Program and the associate program director of the Home Parenteral and Enteral Nutrition (HPEN) Program. The HPEN program at Mayo Clinic assists 700 to 800 patients per year in initiating parenteral (IV) and enteral nutrition (tube feeding) and typically follows 1,700 to 2,000 patients annually who receive nutrition support at home. Within the HPEN program, Dr. Mundi takes a very active role in research with the goal of continuing to improve the quality of home nutrition support.

Beth Gore, PhD, MBA

Beth is a national patient advocate with a background in training, communications, and business. She recently started a job with the Association for Vascular Access (AVA) collaborating with other organizations to help provide safe vascular access. Beth is heading up AVA’s Patient Education and Advocacy Committee.

Beth is a sought-after keynote speaker throughout the health care continuum. She came to Oley initially because of her youngest son, Manny, who lives on home parenteral (IV) and enteral nutrition (tube feeding). Her life mission statement is “Speaking for those who cannot speak for themselves.”

Beth also volunteers as an Oley Ambassador.

She and her husband have adopted six children. To read more about Beth, see the January/February 2015 LifelineLetter.

Bright Idea: Vial Cap Art

As a patient on home parenteral nutrition (HPN), I go through large amounts of trash each night while setting up my “food.” I try to think of ways to reuse some of the packaging, instead of just throwing everything away. I have seen nurses in the past with vial cap badges, and I thought that would be something fun and easy to do.

To make the badge reels, I use a hot glue gun to secure the vial caps. Before the glue dries, I arrange the caps into the shape I want, and then I hold pressure on them until the glue hardens and holds the caps in place. In addition to being on HPN myself, I am also a registered nurse, and my coworkers save their vial caps for me as well.

Combining my own caps and the caps collected on my unit, I have started making a variety of different badge reels. My coworkers look forward to the new seasons, as they get excited for new badge reels. Pictured are some spring ones I have just started working on. The extra “bling” is optional, but I like the uniqueness it gives to each badge!

—Kristi R.
Thank You for Your Support in 2016!

The following list represents everyone who contributed toward Oley's efforts in 2016. We also want to thank those who are not listed below, when three or more gifts are given in honor of, or in memory of, an individual or special event, we’ve created a separate list, which can be

Generous Gifts Without Bounds
The Estate of Doris R. Johnson: $13,000+
The Kuyahoga Valley Foundation's Annual Atlantic (a.k.a., Mac Daddy) Classic Charity Golf Tournament, special thanks to Joy McVey Hugick: $5,000+
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Geoffrey O. Burney
Rick and Dianne Davis, in honor of Oley staff, clinicians, corporate partners, volunteers, and members who have helped Rick during the past fifteen years
Darlene Kelly, MD, PhD***

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Lynda Bosworth, in honor of my favorite sister’s 70th birthday; My Baby and Pep and a wonderful, sweet new year
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Jeffrey and Mary Jo Widmyer, in honor of 27 years of HPN for Mary Jo; includes gift from Liberty Diversified International
Robert Warrington
Betsy Wilson
Patricia Winkle, in memory of Walter Winkle
yet have supported Oley by volunteering their time and talents. Note: found on page 10.

Marion Winkler, PhD, RD, LDN, CNSC, in honor of Betty Hagan RN, extraordinary colleague and friend, in recognition of her devotion
Pam Winter**
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Lynda Bosworth and Bonnie Resig, in memory of Cheryl Rosen and Nancy Shaller; and in honor of Le noce Gollop, “the strongest woman we know!”
Sally Bowers
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Jonathan Brodkin
Colleen Brown
Dale Cosgrove
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Joseph and June Downs
Jim and Joan Eckstein, through Fidelity Charitable grant
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Janelle and Delbert Fortin, in memory of Jonathan Nelson
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Gene and Linda Krautkremer, in memory of Mary Ann Krautkremer
Jill and Jake Krautkremer, in memory of Mary Patnode
Ann LaBorz
Brenda Leake, RN, ET, APN, CWOCN
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Jim and Gloria Wittmann, in honor of Joan Bishop***, Dr. Lyn Howard***, and Don Young
Steve and Valinda Wolfert, in honor of William Wolfert
Mary** and Natalie Wootten
Mary E. Zollars, in honor of John Mahalchak

Contributors ($30–$49)
Anonymous
Anonymous
Anonymous

Donors, cont. pg. 10
Donor News

A few donations were contributed in honor of... 

**March/April 2017**

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Stacy Lee, “Go Natalie Go! You rock!”
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Robert Nichols, in honor of the anonymous donor who so graciously shipped Alan feeding bags
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Maria Smith, in memory of Larry Frantz
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Jay and Carolyn Beek, in honor of Sally and Bill
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**In Honor of Barbara Kirkling**

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Lisa Poveda
Timothy and Amy Ritchey
Monica Ross
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**In Memory of Samantha Bye**

Felice Austin**
Karen Kindle
Lisa** and Ron Metzger

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**In Memory of Ann DeBarbier**

Jean D. Brown
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Pauline Kubizne
Mary Messerle
Lisa** and Ron Metzger
Barbara and Thomas Squadere
Robert Steiner

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**In-Kind Gifts**

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**Matching Gifts**

Autolive ASP, Inc.
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**Fundraisers**

AxelaCare, event at CNW
AmazonSmile, online shopping
Staff of Baxter Healthcare, HPN Awareness Week
Staff of BioScrip Infusion Services, LLC, in Morris Plains, NJ, HPN Awareness Week
Goodsearch/Goodshop, online shopping
The Kuyahoora Valley Foundation’s Annual Atlantic (a.k.a. Mac Daddy) Classic Charity Golf Tournament, special thanks to Joy McVey Hugick Planet Green
Oley Walkathon, see the July/August 2016 Lifeline Letter for list of all participants

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*Oley Trustee
**Oley Ambassador
***Oley Staff

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**March/April 2017**
Topics to be covered at the meeting include, but are not limited to:

- Managing Intestinal Failure
- Transitioning to Independence
- Avoiding HPN Complications
- Why I Need My Dietitian
- Medicare Coverage for HPN
- Reimbursement Overview
- Healthcare Reform: Where Do We Go from Here and What Can We Do?
- Tube Feeding Complications
- Moving Forward with EnFit
- Navigating Skin/Wound Care Issues
- Staying Safe in a Complex Medical World
- Know What’s in Your HPN Bag
- Understanding Lipid Options
- Tips for Parents to Avoid a Medical Child Abuse Diagnosis
- Arranging Advanced Directives
- Understanding Lab Reports
- How Understanding Vascular Access and Potential Complications Can Be Empowering
- The Trend to Blend Your Tube Feeding
- Caring for the Caregiver
- PLUS! Highlights from the XV International Congress of the Intestinal Rehabilitation and Transplant Association (CIRTA) being held in New York City June 28–July 1!

A relaxed, family friendly room has been reserved for families.

Main session presentations will be projected into the room. Children will stay with or close to their parents and other children. Activities/entertainment will be planned in the foyer (just outside of the Family Room) and volunteers will be available to help occupy the children. Comfort stations will be available in the rear of the room.

Afternoon sessions, planned with parents in mind, will be hosted in the Family Room so parents can again stay close to their children. As in the mornings, activities will be planned and volunteers will be available to help occupy the children. Presentations on topics specific to pediatrics, parenting, the medically complex child, and so on will be featured in the Family Room. Special arrangements can be made for a parent to attend a different, specific breakout session if desired. Parents are encouraged to split up and attend different sessions so they return home with as much information as possible.

Silent Auction items needed:

Let’s make this event the best ever! Popular items include: small electronics; jewelry; hand knit or quilted pieces; games/toys; and gift certificates. Bring your contributions with you or contact Cathy at harrinc@mail.amc.edu/(518) 262-5079 to make arrangements to ship.

Last but not least, a new event:

A twist on the traditional wrap up-picnic… Breakfast and Brainstorm-ing! Immediately following the Oley walkathon, we’ll gather for a closing general session filled with expertise, experience, and opportunities to ask questions.

Interact with some of the premier clinicians in the field of home nutrition support and experienced consumers… all eager to help provide you with a better understanding of the therapy that sustains you and how you can live fuller, safer lives. We expect this to be an extremely interactive session with a great exchange of information. Bring your questions! This is a great opportunity to answer a nagging doubt, or clarify something you heard in a session. Updates will be posted www.oley.org as the experts are confirmed.

Upon the conclusion of this special event, we’ll capture photos and bid our farewells. We hope to see there!

Watch your mail for registration information coming soon.
And stay tuned to www.oley.org for updates.
In late-phase clinical trials, possible benefits or risks of a treatment can be identified earlier than they would be in general medical practice. This is because late-phase trials have large groups of similar patients taking the same treatment the same way. These patients are closely watched by Data and Safety Monitoring Boards.

Even if you don’t directly benefit from the results of the clinical trial you take part in, the information gathered can help others and add to scientific knowledge. People who take part in clinical trials are vital to the process of improving medical care. Many people volunteer because they want to help others.

Clinical trials do have risks and some downsides, such as the following:

• The new strategies and treatments being studied aren’t always better than current standard care.
• Even if a new approach benefits some participants, it may not work for you.
• A new treatment may have side effects or risks that doctors don’t know about or expect. This is especially true during phase I and phase II clinical trials.
• Health insurance and health care providers don’t always cover all patient care costs for clinical trials.
• You should learn about the risks and benefits of any clinical trial before you agree to take part in the trial.
• Talk with your doctor about specific trials you’re interested in.

### Scientific Oversight

#### Institutional Review Board

Institutional review boards (IRBs) help provide scientific oversight for clinical trials. An IRB is an independent committee created by the institution that sponsors a clinical trial. IRB members are doctors, statisticians, and community members.

The IRB’s purpose is to ensure that clinical trials are ethical and that the participants’ rights are protected. The IRB reviews the trial’s protocol before the study begins.

An IRB will only approve research that deals with medically important questions in a scientific and responsible way. The IRB also checks on results during the trial. All U.S. clinical trials are required to have an IRB.

#### Office for Human Research Protections

The U.S. Department of Health and Human Services’ (HHS) Office for Human Research Protections (OHRP) oversees all research done or supported by HHS. The OHRP helps protect the rights, welfare, and well-being of research participants. It provides guidance and oversight to the IRBs, develops educational programs and materials, and offers advice on research-related issues.

#### Data Safety Monitoring Board

Every National Institutes of Health (NIH) phase III clinical trial is required to have a Data and Safety Monitoring Board (DSMB).

This board consists of a group of research and study topic experts. The NIH also requires DSMBs for large trials comparing alternative strategies for diagnosis or treatment. In addition, the NIH requires DSMBs for some earlier phase trials that involve high-risk procedures (such as gene therapy) or vulnerable patients (such as children).

A DSMB’s role is to review data from a clinical trial for safety problems or differences in results among different groups. The DSMB also reviews research results from other relevant studies. These results may reveal unknown patient risks, or they may even answer the NIH study’s research question. Scientific oversight informs decisions about a trial while it’s under way. For example, some trials are stopped early if benefits from a strategy or treatment are obvious. That way, wider access to the new strategy can occur sooner. Sponsors also may stop a trial, or part of a trial, early if the strategy or treatment is having harmful effects.

#### Food and Drug Administration

In the United States, the Food and Drug Administration (FDA) provides oversight for clinical trials that are testing new medicines or medical devices. The FDA reviews applications for new medicines and devices before any testing on humans is done, and checks to make sure that the proposed studies have proper informed consent (see below) and protection for human subjects.

The FDA also provides oversight and guidance at various stages throughout the studies. For example, before large-scale phase III trials begin, the FDA provides input on how these studies should be done.

#### Patient Rights: Informed Consent

Informed consent is the process of giving clinical trial participants all of the facts about a trial. This happens before they agree to take part and during the course of the trial. Informed consent includes details about the treatments and tests you may receive and the benefits and risks they may have.

Before you decide whether to enroll in a clinical trial, a doctor or nurse will give you an informed consent form that presents the key facts of the study. If you agree to take part in the trial, you’ll be asked to sign the form.

You can and should ask questions about the trial to make sure you understand what’s involved. Here are some questions to ask before enrolling in a clinical trial:

• What is the purpose of the study?
• Who is sponsoring the study, and who has reviewed and approved it?
• What kinds of tests, medicines, surgery, or devices are involved? Are any procedures painful?
• What are the possible risks, side effects, and benefits of taking part in the study?
• How might this trial affect my daily life? Will I have to be in the hospital?
• How long will the trial last?
- Who will pay for the tests and treatments I receive?
- Will I be reimbursed for other expenses (for example, travel and child care)?
- Who will be in charge of my care?
- What will happen after the trial?

The informed consent document is not a contract. You have the right to withdraw from a study at any time, for any reason. Also, during the trial, you have the right to learn about new risks or findings that emerge. If researchers learn that a treatment harms you, you’ll be removed from the study.

Taking part in a clinical trial is your decision. Talk with your doctor about all of your treatment options. Together, you can make the best choice for you.

**Editor’s Note:** Any clinical trial posted by the Oley Foundation has been reviewed by our research committee and deemed appropriate for home parenteral and enteral consumers.

Reprinted with permission from “News from SPOHNC” (October 2016), the Support for People with Oral and Head and Neck Cancer’s newsletter, with slight changes. Robert L. Ferris, MD, PhD, is the UPMC Endowed Professor, Vice-Chair and Chief of Head and Neck Surgery, and Fellowship Director in Head and Neck Oncologic Surgery.

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**Clinical Conference, from pg. 1**

and borders to further clinical research. At smaller sessions, we learned about blended diets, palliative care, tube and skin care, and more. The Oley booth in the exhibit hall was busy as professionals stopped by to learn more about Oley or to see what was new for their patients. Many thanks to Betty Bond, Bettemarie Bond, and Bob and Mary Smithers for volunteering at the Oley exhibit.

**Lyn Howard Advocacy Award**

At CNW, Brandis Goodman was given ASPEN’s Lyn Howard Nutrition Support Consumer Advocacy Award. Humbled by the experience, Brandis says, “It was such a great honor and really means a lot to me to receive the award.”

Brandis serves as the Director of Parent Education for the Feeding Tube Awareness Foundation (FTAF). She and her husband are the parents of five wonderful children, one of whom is an on tube feeding. Her blog, “Feeding Raya,” chronicles her family’s journey with tube feeding. The blog is cited by hospitals, clinicians, and medical supply companies, and dozens of excerpts have been used in educational settings. Brandis also serves as co-administrator of the FTAF Facebook page, is a contributor to the organization’s parent education resources, and speaks to industry and clinical audiences about pediatric tube feeding. Congratulations, Brandis!  ¶

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ThriveRx specializes in parenteral and enteral nutrition therapies for patients with complex GI disorders.

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Brandis received the Lyn Howard Nutrition Support Consumer Advocacy Award.
Thank You Corporate Partners

Please join the Oley Foundation in thanking our recent corporate contributors. To read about other Oley partners, visit oley.org/PartnerShowcase.

Coram CVS/specialty infusion services
Coram provides comprehensive high-quality infusion care to patients where they live, work or travel. With more than thirty years of experience and nearly 1,200 skilled clinicians, Coram offers personalized, compassionate care. Leading the industry with commitment from the heart, the company maintains a 96 percent patient satisfaction rating.

Option Care
Option Care is a leading provider of home infusion services for nearly forty years. Local, highly experienced teams of pharmacists, nurses and dietitians provide high touch, comprehensive nutrition support to help prevent and treat malnutrition. Option Care supports consumers through its ninety infusion pharmacies across the country.

Functional Formularies®
Functional Formularies® has revolutionized clinical nutrition by offering the world’s first and only certified organic whole food feeding tube formulas and oral meal replacements. Liquid Hope and Nourish are nutritionally complete, non-GMO and contain no added sugar in any form. The products are free of dairy, gluten, soy, and corn.

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

2016 Corporate and Foundation Program Support

The following corporations and foundations gave significant gifts in 2016 to support specific Oley programs.

- Abbott Nutrition
- AxelCare
- Ayco Gives
- B. Braun Medical Inc.
- Baxter International Inc.
- BioScrip
- Bob’s Discount Furniture, LLC
- Coram CVS/specialty infusion services
- Dale Medical Products
- Fresenius Kabi USA
- Global Enteral Device Supplier Association (GEDSA)
- Medtronic
- Nestlé Health Science
- Nutrishare
- Option Care
- Shire
- Short Bowel Syndrome Foundation
- ThriveRx
Notable Individual Gifts
Among the individual contributions received, 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 January 28 through March 3, 2017:

In Honor of
Being on HPN for 34 years; All Oley does to enable patients needing home tube feeding

In Memory of
Samantha Bye; Judith R. Ervin, RN; Lenore Gollop, “the strongest woman we know”; Zoe Allison Hartley; James Nagin; Donald Lester Norton; Josh Shapiro; Colyn Woods; and Don Young, who enriched all of our lives

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.

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 at (800) 776-6539.

- Felice Austin
- Jane Balint, MD
- John Balint, MD
- Joan Bishop
- Ginger Bolinger
- Pat Brown, RN, CNSN
- Faye Clements, RN, BS
- Katherine Cotter
- Jim Cowan
- Rick Davis
- Ann & Paul DeBarbieri
- David & Sheila DeKold
- Dale & Martha Delano
- Tom Diamantidis, PharmD
- Gail Egan, MS, ANP
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- Jerry Fichle
- Don Freeman
- Linda Gold
- Linda Greavenstein
- Deborah Groeber
- The Groeber Family
- Valerie Gyurko, RN
- Alfred Haas
- Shirley Heller
- Alicia Hoelle
- Jeff & Rose Hoelle
- Lyn Howard, MD
- William Hoyt
- Portia & Wallace Hutton
- Kishore Iyer, MD
- Doris R. Johnson
- Darlene Kelly, MD, PhD
- Family of Shirley Klein
- Jim Lacy, RN, BSN, CRNI
- Robin Lang
- Hubert Maiden
- Laura Matarese, PhD, RD, LDN, CNSC, FADA, FASPEN
- Kathleen McIntues
- Michael Medwar
- Meredith Nelson
- Nancy Nicholson
- Rodney Ohamoto, RPh, & Paula Ohamoto
- Kay Oldenburg
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- Susan & Jeffrey Schessual
- Dong Seidner, MD, FACC, CNSP
- Judi Smith
- Steve Swensen
- Cheryl Thompson, PhD, RD, CNSC, & Gregory A. Thompson, MD, MSc
- Cathy Tokarz
- Eleanor & Walter Wilson
- Marion & Larry Winkler
- James Wittmann
- Patty & Darrell Woods
- Rosaline Ann & William Wu

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

- SILVER CIRCLE PARTNERS ($30,000–$49,999)
  - BioScrip, Inc.
  - Coram CVS/specialty infusion services
  - Halyard Health, Inc.
  - Nutrisheke, Inc.

- BRONZE STAR PARTNERS ($20,000–$29,999)
  - Baxter International Inc.
  - Fresenius Kabi USA
  - Medtronic
  - Option Care

- BENEFACCTOR LEVEL PARTNERS ($10,000–$19,999)
  - Abbott Nutrition
  - Functional Formularies
  - Nestlé Health Science

- PATRON LEVEL PARTNERS ($5,000–$9,999)
  - Applied Medical Technology, Inc.
  - Apria Healthcare
  - AxelaCare
  - Cook Medical
  - Real Food Blends
  - Soleo Health
Oley April–September 2017 Calendar

April 11: Oley Webinar, Short Bowel Syndrome: Diet, Hydration and Treatment
April 13: Oley exhibit at Minnesota Association of Vascular Access, Minneapolis, MN
April 25: Oley exhibit at RDs in Practice: Short Bowel Syndrome and Transplant, CHOC, Orange, CA
April 29: Oley Regional Conference, St. Louis, MO
April 29: Oley exhibit at Colorado Vascular Access Network Annual Symposium, Lafayette, CO
May 6: Oley Regional Conference (in conjunction with INS meeting), Minneapolis, MN
May 22–25: Oley exhibit at National Home Infusion Association conference, Orlando, FL
June 20: Oley Webinar, Treatment Options for Gastroparesis
June 28–July 1 (clinicians only): Oley exhibit at Congress of the Intestinal Rehabilitation and Transplant Association, New York, NY
July 5–9: Oley Annual Consumer/Clinician Conference, Old Greenwich, CT

August 7–11: HPN Awareness Week
August 22–26: Oley exhibit at United Ostomy Associations of America conference, Irvine, CA
September 16: Oley Regional Conference (in conjunction with AVA meeting), Phoenix, AZ
September 16–19: Oley exhibit at Association for Vascular Access (AVA) conference, Phoenix, AZ

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

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@mail.amc.edu or (518) 262-5079/(800) 776-6539. Watch for updates on Oley events at www.oley.org.

Additional Meetings of Interest
June 28–July 1: United Mitochondrial Disease Foundation conference, Alexandria, VA
July 12–16: OstoMyFamily, Oklahoma City, OK