How to Write a Winning Insurance Appeal

Brittany Cheree Allen, Esq.

If you’re living with a chronic illness, chances are you’ve had to battle your insurance company for coverage of a treatment, medication, or procedure. This issue is a particular concern for home parenteral and/or enteral nutrition (HPEN) patients since many insurance policies try to exclude coverage for supplemental nutrition. The appeals process can be complex and seem daunting, but you can learn to effectively self-advocate and write a winning insurance appeal by making yourself familiar with the process and following our tips below.

Nationally, although 94 percent of insurance denials are never appealed, approximately 70 percent of health insurance appeals are granted. Insurers are counting on you giving up after receiving a denial, but making the effort to appeal can pay off. The following information should help you navigate the process and write a winning insurance appeal.

Notification of Denial

The first thing you need to do is determine the reason for the denial. There are a lot of ways an insurer can notify you of a denied claim. Your Explanation of Benefits, or “EOB,” can constitute a denial. If your EOB shows that payment was denied, there should be a reason code next to the treatment or procedure. You can find a definition of that code at the bottom of the page or on the back of the EOB. Insurance companies MUST provide the reason for the denial and explain your appeal options, sometimes called “grievances.”

A denial letter may also be sent, to either you or your doctor. Again, the letter MUST indicate the reason for the denial and explain your appeal options.

For more information about your denial, you have the right to request a copy of everything your insurance company relied on in making their determination.

Welcome Ambassadors!

Oley Ambassadors are volunteers. Home parenteral and/or enteral nutrition consumers or caregivers themselves, they are available to help you. Drawing on their own personal experiences, they can answer questions, listen, and share. To find an Ambassador who may have the same diagnosis or therapy, is in your area, etc., visit www.oley.org or call (800) 776-OLEY. Meet our newest Ambassadors.

Tina Jackson

Tina Jackson was born with cerebral palsy, which caused left hemiplegia (paralysis of the arm, leg, and trunk on the left side). She suffered a stroke in 1980 at age twenty-four, which resulted in the loss of the ability to speak and affected her sense of balance. It eventually also affected her ability to eat, and by the age of 44, she was unable to eat without aspirating. At 57, sharing her experiences in the unique lifestyle adjustments she has had make to maintain her independence is one of New Ambassadors, cont. pg. 4

Our First Oley Meeting

Ron Perry

Last June me and my wife, Irene, and granddaughter, Angelique, attended the annual Oley Conference in Cape Cod for the first time. I found the sessions very interesting. The session I enjoyed most was the feeding tube jam session led by Rick Davis. I learned that many people have been on feeding tubes for years and how they coped with the problem of not swallowing.

Another session I found interesting was led by Dr. Stanley Dudrick, one of the pioneers in parenteral nutrition. The workshop on caregivers was informative and allowed us to hear about the emotional drain many caregivers go through. The last session we attended was on dehydration. This stressed the importance of obtaining water and liquids in the body.

This was a well-planned conference with plenty of entertainment and lots of food for the guest. We were able to network with people from around the world. I look forward to attending the 29th annual conference in Orlando, Florida, this June.

Mary Wooten

Words cannot express how alone, scared, and helpless my husband and I felt the day we were sent home from First Conference, cont. pg. 9
Insurance Appeal, from pg. 1

Requests for such information should be made in writing and you should clearly state your request does not constitute your appeal (we usually write “THIS IS NOT AN APPEAL” at the top of the request).

Basis of Denial

There are two main categories of denials: medical necessity and experimental or investigational. Medical necessity involves proving you meet the requirements for treatment. Experimental/investigational involves showing the requested treatment is safe and effective based on current research studies and medical journal articles, and that it is medically necessary.

You should look at your insurance policy. If the denial is based on policy language, you’ll want to see the language. You should search your insurer’s Web site, usually in the members’ area, to look for their medical policies, called “clinical policy bulletins” (CPBs). These are detailed papers written by or for insurers that outline all of the coverage policies, including citations to medical journal articles and other sources your insurer relied on in making their decision. The CPB will tell you what factors are considered in determining medical necessity.

For example, one insurance company’s CPB regarding the use of formulas and enteral nutrition (EN) states it covers them when the requested formula/EN is expected to provide more than 50 percent of the member’s daily caloric intake. So, if you receive a denial under this plan stating EN is not medically necessary, you would need to provide documentation (medical records) showing that you meet the 50 percent threshold.

If there is an express exclusion for a particular treatment in your policy, like over-the-counter nutritional supplements, your insurance most likely won’t cover it and an appeal would be unsuccessful.

Preparing Your Appeal

If your denial was based on medical necessity, you’ll need to collect your medical records in order to explain why the treatment is medically necessary. You should collect relevant office notes, x-ray reports, blood tests, other diagnostic tests, and hospitalization records. This provides the insurance company objective medical information to back up your subjective description of symptoms.

If your denial was based on experimental/investigational, in addition to collecting your medical records, you must also show support for the use of the treatment in the medical literature. You can find medical journal articles at www.pubmed.gov or Google Scholar. Generally using your condition and treatment as search terms produces good results. Full text articles can be retrieved at medical libraries (typically at your state university) for free, or you can pay per article online. Abstracts of the articles, which are free online, can be used in place of full text articles if you are unable to obtain the full text copy. It sounds super technical, but spend some time reading abstracts and you’ll quickly figure out how to read and understand the results.

Deadlines

Appeal filing deadlines are very important. Typically you have 180 days from the date of the denial to file your first-level appeal. If your insurance company upholds its denial, you may have to file a second-level appeal before proceeding to external review (if available). The second-level deadlines can be much shorter.

This information should be contained in your denial letter, but you can also find out by contacting the customer service number on the back of your insurance ID card. You have 120 days (or four months) to file for an external review. External reviews are conducted by organizations independent from the insurance company and we have had a lot of success at this level. However, missing a deadline cuts off your eligibility for further review, so it is very important to keep track of deadlines.

Outline of the Appeal Letter

Once you’ve collected all of the necessary documents, it’s time to write your appeal letter. You should include the following elements.

Identifying information: include the patient’s name, insurance ID number, Social Security number, and date of birth, as well as a claim reference number if one was provided.

Medical necessity summary: if you have information from the CPB, format this section of your appeal letter to match the format used in the policy. Start with the diagnosis, including objective support in the medical records like weight loss, recent test results, radiology reports, etc. Then identify what treatments have been tried and failed. This is an important step for both medical necessity and experimental/investigational appeals because it shows that the treatment requested is the only/best option available.
Solution for Clogged Tubes

If your feeding tube is clogged, the first step is to try flushing with warm water. When that doesn’t work, your clinician has some new tools available to resolve the issue. Further advice on preventing and treating clogged tubes can be found in Oley’s Tube Feeding Troubleshooting Guide, available at www.oley.org or by calling (800) 776-OLEY. Note: these methods should not be used with intravenous lines.

Viokace® Tablets

This solution to clogged G- and J-tubes relies on the action of a pancreatic enzyme and sodium bicarbonate, and is recommended when a feeding tube is blocked by nutritional formula. Viokace® (Aptalis Pharma) is the only pancreatic enzyme recommended for this off-label use because it does not have an enteric coating (a substance on the outside of medication designed to prevent the medication from dissolving in the stomach). An enteric coating may prevent the enzyme from dissolving the clog, and end up clogging the tube further.

Viokace is available by prescription, and the following method is recommended for use by clinicians only. Note: if the clog is not made of formula, the enzyme may not dissolve the clog and may leave a gummy residue that can increase the size of the obstruction. Also, use caution when clearing small-bore tubes, as tablet fragments may further complicate the clog. Viokace contains lactose monohydrate, which may not be tolerated by patients with lactose issues.

Method: Wearing gloves and a mask, crush one Viokace tablet (10,440 USP units of lipase) and one 375 mg sodium bicarbonate tablet, and mix in 5 mL of water. Introduce the mixture into the clogged tube, clamp, and let dwell for at least 30 minutes. (The mixture can be introduced with a syringe; or if the clog is further down the tube, it can be introduced with a small-bore PVC tube inserted into the feeding tube.) Next attempt to flush the tube with warm water. If the clog is not cleared, the old Viokace mixture should be removed from the tube and replaced with a fresh batch.

Many thanks to Mark Klang, MS, RPh, BCNSP, PhD, for sharing his research. (Klang, M. et. al., [2013] Dissolving a Nutrition Clog With a New Pancreatic Enzyme Formulation. Nutrition in Clinical Practice, 28[3], 410-411.)

Clog Zapper™

The Clog Zapper™ (Corpak MedSystems) uses a patented, food-grade powder that the manufacturer calls an “enzyme cocktail” (with acids, buffers, anti-bacterial agents, and metal inhibitors) to clear blocked tubes. It comes premeasured and loaded in a ready-to-use system, and is approved for use with G-, J-, NG-, and NJ-tubes as well as low-profile devices.

This powder “cocktail” is mixed with water in a syringe and agitated for 5–7 minutes. The solution is dispensed through a narrow-bore applicator tube which is placed into the feeding tube. Once the solution is instilled wait 30–60 minutes. Take a separate syringe with water and flush the tube to relieve the obstruction. It is recommended that the first time you try the Clog Zapper you do so under a clinician’s supervision.

TubeClear®

This solution to clogged tubes relies on mechanical cleaning action (like snakeing a clogged drain) and can be used by a clinician to clear different types of substances that may block a G-, J-, NG- or NJ-tube. The TubeClear (Actuated Medical, Inc.) electronic control box feeds disposable “stems” (like miniature bottle brushes) into a feeding tube. Once the stem reaches the blockage, an automated in-and-out motion is used to clear the obstruction through vibration. Often the stem is fed more than once, and water may be inserted and/or loosened clog contents may be aspirated to assist the clearing process.

TubeClear can only be used if the clinician knows for certain the type, size, and length of the feeding tube. Potential injury to the gastrointestinal tract (ulceration, bleeding, and very rarely, perforation) may occur if the device is inserted beyond the distal end of the feeding tube. The clinician must verify that the tube is still properly placed after the procedure.

This device is approved for use by the U.S. Food and Drug Administration (FDA) and is currently undergoing clinical trials, but results have not yet been published in a peer-reviewed journal.

Bionix® DeClogger

The DeClogger is a thin, flexible, polypropylene rod that has a spiral tip on one end and a handle on the other. It comes in two different lengths and five widths (French); each size is a distinct color. The rods are marked along their length to prevent over-insertion. As with other mechanical tube-clearing devices, the clinician must know the type, size, and length of the feeding tube. Potential injury to the gastrointestinal tract (ulceration, bleeding, and very rarely, perforation) may occur if the device is inserted beyond the distal end of the feeding tube. There is also a chance that the tube itself may be damaged.

The DeClogger is designed to be inserted into the tube, then gently twisted. When twisted, the screw-thread design of the DeClogger allows it to bore through and loosen a clog. It is available only on the order of a clinician.

Oley member Errol Childress (woodznjo@gmail.com) writes, “I love the DeClogger. You screw the rod into the tube, pull out the clog, then flush. So simple to use!” Go to www.oley.org or call 800-776-6539 for the rest of Errol’s letter, including his advice to follow manufacturer’s “single-use” recommendation and to loosen any tube securement device before using.

PEG Cleaning Brush

Bard manufactures brushes that are made specifically for cleaning PEG tubes. The brush is designed for daily or weekly cleaning of tubes 20 French or larger; it is not designed to loosen clogs. It has a brush tip (feather mounted to help “minimize the risk of mucosal injury”) on a nylon shaft, with a luer hub so fluids can be injected into the tube simultaneously with the brush. Potential injury to the gastrointestinal tract (ulceration, bleeding, and very rarely, perforation) may occur if the device is inserted beyond the distal end of the feeding tube. There is also a chance that the tube itself may be damaged.
the things she can offer as an Oley Ambassador, as well as listen to others share their struggles.

Tina earned a bachelor’s degree in social work in 1977 and an associate’s degree in medical records, along with completing an office administrative clerk course, in 1984. She has worked as a social worker, director of medical records, and clerk. Currently, she and her husband, Mark, market a stand designed to make bolus tube feeding more manageable.

Tina is also a volunteer co-organizer of the Appalachian Bike Tour. She has been instrumental in planning and organizing this annual scholarship fund-raiser since 1998. Further, she serves as a member of Kentucky’s Commonwealth Council for Developmental Disabilities.

Tina can be reached at tinaj@gmail.com.

Stephanie Labelle

Stephanie Labelle has been an Oley Ambassador for a while—you may have already reached out to her—but we haven’t yet had the opportunity to properly welcome her. Stephanie is the mother of William, who was born in 2008. From birth, William has had trouble with reflux, dysmotility, low platelets, big spleen, and low immune system. He has to be on nutrition support because he cannot eat normally. William is on home parenteral nutrition (HPN) fifteen hours a day and on home enteral nutrition (HEN) for hydration four times a day. “Despite all the investigations and testing,” Stephanie says, “the doctors haven’t yet found what is causing all the problems.”

Stephanie had worked as an events and banquets coordinator, but left her job to stay home and take care of William full-time. They live in St-Hippolyte, Quebec, a one-hour drive from Montreal, where William is a patient at the intensive ambulatory home care service. William is in kindergarten, but, Stephanie says, his health makes it impossible for him to attend on a regular basis.

“My goal,” Stephanie says, “is to talk to people (in English or French), to share by phone or e-mail. I want to raise awareness, to get more support from government and social services, and to find ways to cope more easily with HPN on a daily basis for travelling, attending school, and with insurance issues.” Stephanie can be reached at 10, 347th Ave., St-Hippolyte Quebec, Canada; (450) 563-2409; or labelle_steph@hotmail.com.

Don Lacey

Don says “the most significant [thing in my life] is my forty-three year marriage to my wife, Sandy.” Sandy has been on home parenteral nutrition (HPN) since 1982. “The challenges associated with the evolving technology and treatment has been a gratifying ‘Life’ experience,” says Don.

Don spent forty-plus years working as a technical consultant in the food industry, and has travelled extensively for work. He was elected to the Royal Institute of Public Health, and was recognized for his expertise in water treatment/water quality issues, and food-borne illness associated with commercially processed foods. “I like to think my technical background has enabled me to be a source of support to Sandy,” Don adds.

Don is “a true believer in life-long learning,” and has degrees in psychology, microbiology, administrative studies, environmental studies, and adult education. He is currently pursuing an Honors Degree in Health Studies Policy Management. He and Sandy also enjoy spending time with their two wonderful granddaughters.

“Sandy and I both look forward to establishing a close, collaborative, rewarding, working relationship with Oley,” Don notes. Don lives in Oshawa, Ontario, and is working with health care providers and other homePEN consumers and caregivers to establish a support group in the Toronto area. He can be reached at sandy_lacey@sympatico.ca or (905) 579-4737 (Canada).

Colin Waddell

Colin Waddell was born in Vancouver and has lived in British Columbia for most of his life. Radiation treatments for throat cancer damaged his mouth and throat, and eventually he had to have a PEG tube placed (in November 2012). “Already depressed,” he says, “I moved into despair before discovering Oley. With the direction of Oley staff, several Ambassadors came to my rescue, helping me to realize that tube feeding was not the end of the world.”

Colin is active on the Oley forum. Through his activity there, he says, “I came to understand why the Oley forum is named Inspire.” He continues, “I now live a fairly ‘normal’ life and want to provide help and reassurance to others who may be in similar straits.” Colin can be reached at 9107-98a Ave., Fort St John, BC, Canada V1J 5G8; (250) 787-1504; or colin@cobatoma.com.
Book Corner

Review by Robin Bodnar

While at the 2013 Oley conference in Cape Cod, I purchased the book *Just Another Run of the Mill Day*, by Leah Atkinson. I had met Leah and her son Jameson at the 2010 Oley conference. My son, Andrew, had suffered a mid gut volvulus in December 2009, and Jameson had gone through the same thing in May 2001. Both boys were in their teens and in high school when this happened to them.

*Just Another Run of the Mill Day* is the story of that journey, and the ripple effects that can happen in a family when a catastrophic medical event changes everything. Leah says, “It is said that life can change in the blink of an eye. I blinked.” This quote truly summarizes the book’s content.

For me, this book was very easy to read, yet emotionally draining. I shed many tears, yet could not put it down. For three years prior, we had been living the first half of its story, but I had never had time to think about it. While reading, my heart sank as memories came flooding back. I am so thankful to have met the Atkinsons early in our journey. Because they traveled the road before us, they helped clear the way, and were a wonderful God sent gift of mentors to us.

Ripple Effects

Most people [in the general public] could probably relate more to the second half of the book [which is more about Leah’s younger son, Ross], because very few go through what happened in the first half. For me it was the opposite. I lived the first half. With that said, I could empathize with Leah’s journey with Ross. First, I have to say, it is so easy to judge someone whose children are in crisis. Having survived two of my three children’s teenage years (Andrew is still a teen), I could easily have fallen into that trap.

My children are well-adjusted and on their way to living productive lives. But had Andrew gotten sick when his siblings were younger, I think their outcome would have been so different. We wouldn’t have had the time to devote to them. My children were/are “good kids.” But my older son made sure to practice the art of drinking underage so that he could perfect it for when he was legal. I spent many nights praying and crying that he would come home safely. My daughter was such a perfectionist that we worried she would have ulcers by the time she was six. Andrew even had his own skirmish with the law.

When Andrew got sick, my children were young adults, who got put aside. Matthew came home from US Marine Corps training to find his brother in the ICU. He was put aside at Christmas, during his entire leave, so we could be at Andrew’s bedside. I worried, and apologized continually about the time I was not spending with my older children while Andrew was hospitalized. Had they been younger, like Ross, how would they have handled it? Would they have gotten angry? Would they have been afraid? Would their hearts have hurt? Would they have cried out for attention? Most likely, yes, they would have. Would they have turned to drugs and/or alcohol, to ease their anger, fear, and pain?

Book Corner, cont. pg. 10 ➔
Thank You for Your Support in 2013!
The following list represents everyone who contributed toward Oley's efforts in 2013. We also want to thank those who are not listed below,

**Ambassadors ($2,000+)**
Steven N. and Leah Atkinson
Rick and Dianne Davis
Darlene Kelly, MD, PhD
Jack and Carol Leibee
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**March/April 2014**

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Help along the way

29th Annual Consumer/Clinician Conference
June 23–27, 2014
Renaissance Orlando at SeaWorld
Orlando, FL

Registration Packet

"The conference could not have been a more positive experience for us. We are so grateful for the opportunity to attend!"

"A whole new world opened up to me when I attended my first Oley conference."

"This is the most important, life-changing conference.... [It] has made me a better clinician."
For More Information
For the latest updates (faculty list, etc.), check www.oley.org/annualconf.html; call the Oley Foundation at (518) 262-5079 or (800) 776-OLEY; or e-mail harrinc@mail.amc.edu.

Registration—Free for Consumers/Families
Minimal fee for professionals (see back page). Register at www.oley.org or complete the form on the next page. Registrants are responsible for their own hotel and transportation arrangements.

Main Sessions & Breakout Sessions—Learning Opportunities Abound!
Presentations are coordinated to boost your understanding of the therapies that sustain you or your loved one. Topics covered formally on Tuesday include: The New Treatment for Short Bowel Syndrome, Staying Connected... as Enteral Tubes Roll Out, and Bacterial Overgrowth. Topics addressed on Wednesday include: Why Advocating for Yourself and/or Your Child Is Important, Growing New Bowel: Future Care for Short Bowel Syndrome and Trends in Managing Intestinal Failure.

Tube Feeding Workshop
A must for tube feeders. You’ll learn about: Keeping Complication to a Minimum, Formula and Medication Compatibility, More on New Connectors, Formula Options and Tube Choices, and More on Blenderized Diet.

Ambassador Workshop/Volunteer Info Session
Planned for “official” Oley volunteers, but open to everyone with an interest in serving Oley, whether through outreach, social networking, graphic design, etc. Learn more about how to share your time and talents to advance the Oley mission. For more information contact Lisa at metzgel@mail.amc.edu or (800) 776-OLEY.

Child Care/Youth Activities/Jammin’ Jammies
Complimentary child care will be available Tuesday and Wednesday during the educational sessions. Chaperoned activities are planned for children ages 7+ on Tuesday and Wednesday afternoons, as well as a pajama party on Wednesday evening that is always a hit! Children/youth must be registered online by June 18 to participate in these activities. If you don’t have access to the Internet call (800) 776-OLEY to register your child/youth.

Walk-A-Thon Raises Funds, Awareness
Join us for a short walk. Forms to gather sponsors for this event and help raise awareness are available at www.oley.org or call (800) 776-OLEY.

No-Host Farewell Breakfast
We’ll gather in the Trade Winds Restaurant, order off the menu, exchange parting wishes, and enjoy being surrounded by Oley attendees one last time before leaving for home. To be included in this group reservation please indicate the number of people in your party.

Market Research
Share your experience with tube and/or IV feeding to help improve the next generation of products—and get compensated for your time! Indicate your interest on the registration form. Opportunities are limited and available to qualified participants on a first-come, first-served basis.

Why Should I Attend?
Proven Benefits to Patients in Contact with Oley*
• Lower incidence of catheter-related sepsis.
• Reduced reactive depression.
• Significantly improved quality of life.

More Reasons ...
• Learn to communicate your health care and emotional needs with more self-assurance.
• Meet others on home tube and/or IV feeding.
• Clinicians—learn and become better resources.

Plus! Oley Provides a “Safe Harbor”
• Local emergency room information will be identified.
• Nursing/pharmacy backup support has been arranged.
• Hotel is aware of your supplies and shipping needs.
  • Rooms have refrigerators.


“I learned things and met people that changed my life.”
**Program-At-A-Glance**

**Monday, June 23**
- 1:00 pm – 5:00 pm Early Registration
- 1:00 pm – 6:00 pm Ambassador Workshop/Volunteer Info Session
- 6:00 pm – 7:00 pm First-Time Conference Attendee Orientation
- 7:00 pm – 9:00 pm Welcome Reception/Awards Ceremony/Talent Show!

**Tuesday, June 24**
- 8:00 am – 4:30 pm Registration/Information
- 9:00 am – 12:00 pm Main Session
- 12:00 pm – 2:00 pm Exhibits
- 2:15 pm – 4:30 pm Tube Feeding Workshop
- 2:15 pm – 3:15 pm & 3:30 pm – 4:30 pm Breakout Sessions (attend two groups, see partial list below*)
- 7:30 pm – 9:00 pm Oley Silent Auction

**Wednesday, June 25**
- 8:00 am – 4:30 pm Registration/Information
- 9:00 am – 11:45 am Main Session
- 11:45 am – 12:00 pm In Loving Memory
- 12:00 pm – 2:00 pm Exhibits Raffle Day
- 2:15 pm – 3:15 pm & 3:30 pm – 4:30 pm Breakout Sessions (attend two groups, see partial list below*)
- 8:00 pm – 10:00 pm Jammin’ Jammies

**Thursday, June 26**
- 11:00 am – 5:00 pm Oley Walk-A-Thon/Picnic

**Friday, June 27**
- 10:00 am – 12:00 pm No-Host Farewell Breakfast

*Breakout Session Topics*
...will include, but are not limited to the following. Stay tuned to www.oley.org/annualconf.html for updates.

- Navigating Catheter Complications
- Nutrition Jeopardy
- Let’s Talk About Catheter Locks
- Me Stressed? Who’s Running Whom?
- Managing Pediatric Short Bowel Syndrome
- What’s in Your HPN Bag?
- Is Gattex for You?
- Drug Shortages and Your HPN Bag
- Communicating with Clinicians for Best Outcome
- Addressing Leaky G or J Tubes
- Skin/Wound Care
- Arranging the Best IEPs
- Food Allergies and Sensitivities
- Diet, Fluids and Conventional Medicine
- Practical Approach to Managing Diarrhea
- Combining HPN and HEN Therapies

---

**2014 Oley Conference Registration Form**

**GENERAL INFORMATION**

Register at www.oley.org/2014ConfReg, or complete one form per adult.

- ☐ This is my first Oley conference!

**Name ________________________________________________**

**Address _______________________________________________**

**City __________________________ ST ______ Zip __________**

**Phone (Day) ___________ – ___________ – ____________**

**Phone (Cell) ___________ – ___________ – ____________**

**E-mail: ______________________@________________________**

- ☐ Yes, I want to help with market research! I plan to arrive 6/_____/14 at _____:_____ am/pm

- ☐ Yes, I want to help with market research! I plan to depart 6/_____/14 at _____:_____ am/pm

**HomePEN Consumers/Patients:**
- Primary Diagnosis ________________________________________
- Began IV/Tube Feeding ______/______/______ (Month/Day/Year)
- Catheter/Tube Type ______________________________________
- Homecare Company _____________________________________

**Clinicians/Professionals:**
- Title __________________________________________________
- Organization ____________________________________________
- Specialty _______________________________________________

**AFFILIATIONS**

Please check (✓) ALL that apply:

- ☐ HPN consumer (TPN, IV fed, parenteral or hyperal patient)
- ☐ HEN consumer (tube fed or enteral patient)
- ☐ Family member/caregiver: ________________________
- ☐ Faculty
- ☐ Physician
- ☐ Nurse
- ☐ Dietitian
- ☐ Pharmacist
- ☐ Other _________________

**CHILDREN/YOUTH REGISTRATION**

Children/youth must be registered online at www.oley.org by June 18 to participate in child care, youth activities or Jammin’ Jammies. If you don’t have access to the Internet call (800) 776-OLEY to register your child/youth.
Getting to the Hotel and Around Orlando

Flying: Orlando International Airport (MCO) is 13 miles from the Renaissance Hotel. Mears Shuttle Service costs $19 one way, $30 roundtrip (800-759-5219, www.mearstransportation.com). Details on how the shuttle service works and a coupon for $4 off a roundtrip fare are available from their Web site; click on the “Book Orlando Airport Shuttles” icon, then enter your booking information and priority code 471678201. No Internet? Call (800) 776-OLEY for a copy of the coupon and buy your ticket when you arrive at the airport. Taxi fare is estimated to be $40 one way.

Come early or stay longer to explore Orlando. The I-Ride Trolley stops just outside the Renaissance hotel and runs daily 8:00 a.m. to 10:30 p.m. to major attractions, shopping, and dining. For rates, map, and other details go to www.iridetrolley.com or call (407) 248-9590.

Travel Grants for First-Time Conference Attendees!

Thanks to generous donors who believe the conference is extremely beneficial, there are several $500 travel scholarships available for consumers who will be attending the Oley annual conference for the first time, and for Oley Ambassadors. Applicants should not be receiving any other financial assistance from homecare companies, etc. for travel and/or lodging expenses related to attending the conference.

Qualified conference attendees should write two paragraphs describing how they believe attending the conference will affect their life and submit them to harrinc@mail.amc.edu or The Oley Foundation, 43 New Scotland Ave., MC-28, Albany Medical Center, Albany, NY 12208. The ideal candidate will also describe their plans to share information learned at the conference with consumers and/or clinicians back home. Travel must be completed and receipts received by Oley before reimbursement can be made.

Other Ideas to Help with Travel

- Compassion flights from Air Charity Network or similar group (www.oley.org/Medical_Air_Transportation.html).
- Financial help from United Way, Kiwanis, Rotary or Lions clubs, churches or synagogues, disease-specific and wish-granting organizations (www.oley.org/Wish_Granting.html).
- Travel tips and planning (www.oley.org/traveltips.html).

Hope to See You There!

Conference Coordinator: Joan Bishop
Conference Co-Chairs: Paula Johns, RN, CNSN Bob & Mary Smithers

Some of your meals are covered at the conference!

In an effort to keep the conference affordable, generous supporters have underwritten some of the meals during the conference.
yet have supported Oley by volunteering their time and talents.

Brenda Hansen
Charles Kamack
Rachel Lopez
Paulette Mabardy
Tiffany Matthews
Angela McAvoy
Nora Medwar
Dolores Metzger
Pat Mielke
Phillipe Moyen
Marilyn Murray, in honor of Brad Murray
Meredith Nelson
Elizabeth Pemble
Peggy Roth
Stacey Rothmeyer
David Rowland
Karen Smollen
Betty Zeller, in honor of Kim Zeller

Friends (Up to $30)
Balani Aklufi
Ann Alford
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Anonymous, through United Way of the Greater Capital Region
Peggy Aschenbeck
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Denis Benoit
Adele Bixworth
Eileen Bowes
Jonathan Brodkin
Karen Brust
Diane Chmel
Peggy Christ
Kathleen Cohen
Coryn Commare, in honor of Art Commare for his courage and determination
Jean Cox
Sandis Croner
Aparna Dagar
Linda Deane
Stephanie Degraw
Gretchen DeKalb, in honor of Mary Kunz’s birthday
Anne De Lange
Jean Demichelli, in memory of Josh Shapiro
Dante D’Orio
Domenick Fama
Eileen Fisher
Robert Freeman
Susan Friebel
Jacqueline Goldman
Jennifer Grasso
Linda Gulden
LuAnn and Ronald Harris
Stephen J. Harris
Teresa Hillary
Susan and David Hillman
The Hoelle family
Noreen Iacobucci, in memory of Joyce Hydorn
Carol Ireton-Jones, PhD, RDN, LD, CNSC, FASPE
Helga Johnson
Heather King
Marek Lichota
Sharon Lynch
Craig, Shannon, and Alyssa MacCormack
Elizabeth Anne Mahoney
Mary Meador, in honor of Tegan
Sandra Michaud
Patricia Miller
Donna Mummary
Nancy Newton
Timothy Newton
Howard and La Yonne Nicholson
Dori Pedrilli
Arthur Pettigrove
Susan Proulx
Raymond Raizyky
Jennifer Rath
Sarah and Jim Rausch
Lakshmi Rebpragada
Carlene Renaud
Kim Sam
Danny Sekelsky
Jason Shearrow, in honor of Colorado State Infusion
Randise Simon, in honor of Alexander Topping
Bob and Mary Smithers
Peter Sneeringer
Jeanne Steinborn
Ruby Stoudenmire
Joanne Sundling
Philip Sweeney
Bryan Tims, in honor of the love and caregiving of Kay and Roger Tims
May To
Mary K. Van Kleunen, in memory of Andrew Van Kleunen
Scott Wassel
Susan and Jerry Weinman, in honor of Liz and Joe Greenberg’s 50th anniversary
Sheila Winfrey
Donna Wisnaskas
Carol Witzlin
Maria Zimmerman

In Honor of Tim and Barbara Squadere, on their anniversary
Jeanne Cosco
Jack and Debra Cottrell
Paul DeBarbieri

Donors, cont. pg. 8 ➔
EXCEPTIONAL SERVICE, CARE & SUPPORT

E N H A N C E D QUALITY OF LIFE

At Coram, our patient care goes beyond providing safe, effective home nutrition therapy. From our Patient Advocates to our experienced clinicians, our entire staff works to support consumer quality of life. Our consumers know that Coram has their home nutrition support needs covered so they can go out and enjoy life!

“We are so delighted with every aspect of Coram. Your people really care! Thank you all from the bottom of my heart!”

— Coram Nutrition Consumer

Donors, from pg. 7

Carolyn Friedman
Deann Squadere
Ronald Squadere and Marcia Cappuccilli

In Memory of Alisha Hoelle
Greg and Melissa Antonelli
Felice Austin and Mariah Abercrombie
Rose Baiocco
Grace Catando
Charlene Comphere, PhD, RD, FADA, CNSC, LDN
Barbara Cucinotta
Joseph Cucinotta
Cara Elias
Jessica and Paul Ferguson
Mario Gentile
Gloucester County Historical Society
Delores Greenwood
Cailen Linde
Joan and Eli Medwar
Michael Medwar
Lisa and Ron Metzger
Mary Miller
Tammy Morris
The Oliveri Family
Jerry Pitts
Janet Platt and Sanford Schimel
Chuck and Cathy Torella
Lillian Van Tilburg
Paul and Mary Walter
Allan and Cheryl Yelner

In Memory of Mary Alice Kaufman
and in Honor of John Mahalchak
Crafton Elementary School
Sandy and Dominic Talotta
Elsa R. Zollars

In Memory of Eleanor Orkis
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Fred and Esther Muscanell
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Kurt and Margaret Muscanell
Jennifer Orkis
William Orkis
James and Mary Smith
Susan and Dan Staver
Syracuse Obedience Training Club
Debra Wein
Agnes White

In Memory of Robert White, Jr.
Kevin and Maria Cahill
Jeanne Cahill Davis
Mary A. De Blasio
Judith Foldes
Jeannette Graf
Nancy Graf
Jarrod Grasso
Betty Hershan
Lynn Karlson
Peter Longo
Diane Montemurro
New Jersey Multiple Listing Service, Inc.
Palisades Park Education Association

Matching Gifts
Allstate Giving Campaign
Bank of America Charitable Foundation
FM Global Foundation
The GE Foundation
Jones Lang LaSalle
National Grid

Zumba-Thon
Thanks to the following for generating donations and participating in the Zumba-Thon at the annual conference.
Pat Anthony, MS, RD
David and Miranda Einstein
Fresenius Kabi PN Team
Ray Gravenstein
Rose and Alicia Hoelle
Marek Lichota
Rachael Lopez
Eli Medwar
Michael Medwar
Alyce Newton, CNSC, LDN
The Rath family
Mary Smithers
Peter and Donna Yadrich, MPA, CCRP

Fundraisers/Grants
Mary Ellen Costa’s handmade bracelet sale
Fidelity Charitable Grants
Good Search
iGive.com
Planet Green

Thank you!

WeNourish.com | 877.WeNourish

8 — LifelineLetter • (800) 776-OLEY

March/April 2014
Awareness Week Recap

The Oley Foundation once again joined the Feeding Tube Awareness Foundation in promoting Feeding Tube Awareness Week, held February 9–15. Thanks to all of the Oley members who shared stories, buttons, photos, Facebook comments, and videos. We distributed 2,500 buttons with your help!

If you haven’t yet seen Oley’s Feeding Tube Awareness video, you can watch it on Youtube.com/TheOleyFoundation. We’d be happy to add your awareness videos to our channel, too. You can find links to some of the news stories and videos about the week on www.oley.org (go to “more news”) or www.feedingtubeawareness.com. If we missed your effort, please let Lisa know at metzgel@mail.amc.edu or (800) 776-6539.

Finally, mark your calendar for HPN Awareness Week, August 3–9, and the next Feeding Tube Awareness Week, February 8–14, 2015. ¶

Insurance Appeal, from pg. 2

If you are filing an experimental/investigation appeal, you need to address the medical literature. You want to start with the strongest support, which would be randomized, placebo-controlled studies, and then branch out to the less persuasive articles, like review articles. Sometimes you can include other insurance companies’ policies that allow for the treatment you are appealing, especially if it is an affiliate of your insurance company (like the Blue Crosses). You will also need to include a medical necessity summary to show why the treatment/procedure is indicated for the patient (you) at this time. You can outline symptoms, flare-ups, negative reactions, etc., documented in the medical records. You can also reference any recommendations in the medical records from your treatment providers.

Resources

Keep in mind that your health care provider is a great resource when appealing a denial. If you offer to take the burden of writing the appeal off his or her shoulders, it will be easier to get his or her help reviewing medical literature and analyzing insurance medical policies. You can often get letters detailing the medical necessity directly from your provider as well. Just ask.

For an example of a medical necessity enteral formula appeal letter, go to www.oley.org. For more information on how to file appeals and other resources, please visit the Jennifer Jaff Center Web site at www.thejenniferjaffcenter.org or call (860) 674-1370. ¶

First Conference, from pg. 1

the hospital with our seventeen-month-old daughter Natalie and her brand new feeding tube….When Natalie was just shy of four years old, someone asked if asked if we had ever heard of the Oley Foundation… I found Oley’s site on the Internet [and] it was like finding a home we didn’t know we had. There really were other kids and adults with feeding tubes?! Other parents were having the same doubts, troubles, and fears that we were having?!

Natalie was so excited to go to the conference in Cape Cod and meet other children with “tubies.” Our first night there, Natalie proudly walked through the halls with her backpack. Our five-year-old daughter finally felt like she belonged! She could play with kids and not have to feel self-conscious or have to explain what her tube was for. We loved talking to all the vendors and learning about new supplies to make life with a tube so much easier for Natalie, and us as her caregivers. ¶
Corporate Partner Spotlight

Please join the Oley Foundation in thanking our most recent corporate contributor who helps keep Oley programs free of charge to home parenteral and enteral consumers. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

Fresenius Kabi

Fresenius Kabi is dedicated to caring for critically and chronically ill patients by providing intravenously administered drugs, infusion therapies, clinical nutrition, and related medical devices—both in hospitals and in outpatient care settings.

“Throughout our long history,” they write, “we have been driven by excellence and innovation, and those ideals continue to inform our work today. As a global healthcare company, we are positioned to meet the needs of our customers and patients worldwide. Each day, more than 23,000 employees affirm our commitment to ‘caring for life’ and dedicate themselves to what we believe matters most in healthcare: improving patients’ quality of life.”

Book Corner, from pg. 5

Children want attention, good or bad. They will take any they can get. At the time when your child is on life support, you do not tend to think about the effects on your other children. Then, when you find out there are lifelong medical issues that your child now faces, how does that affect your other children?

I want to thank Leah for sharing her heart. It could not have been easy to write this book, and to share so honestly, her journey. I also want to thank the Atkinson family for allowing her to share their wrinkles, warts, and scars. At times when life gets hard, and I feel so alone in this journey, I think of the Atkinsons and remember we are not alone on this trail. Others have traveled this path before us.

2013 Corporate & Foundation Program Support

The following corporations and foundations gave significant gifts in 2013 to support specific Oley programs:

- Abbott Nutrition
- Applied Medical Technology
- B. Braun Medical
- Baxter Health Care
- CERA Products
- Coram Specialty Infusion Services
- Covidien
- Fresenius Kabi USA, LLC
- Functional Formularies
- Kimberly-Clark
- Moog Medical Devices
- NPS Pharma
- Nutrishare, Inc.
- Daniel F. and Ada L. Rice Foundation
- Sherwood Clinical
- ThriveRx
- Walgreens Infusion Services

America’s Premier HPN Pharmacy

Created Exclusively for Long-term Home TPN Consumers

Why Choose Nutrishare?

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Empowering TPN consumers to choose their supplies and equipment.
Leaders in HPN Research.
Personal assistance for all insurance and billing matters from Nutrishare’s home-team of reimbursement specialists.
Opportunities for our ‘Family of Consumers’ to network with each other.

Serving TPN Consumers Nationwide

Nutrishare

1 800 HOME TPN

23 Years of Home TPN Dedication

Helping our family of consumers reach a greater quality of life

2014 Corporate Foundation Partner

Fresenius Kabi

Fresenius Kabi is dedicated to caring for critically and chronically ill patients by providing intravenously administered drugs, infusion therapies, clinical nutrition, and related medical devices—both in hospitals and in outpatient care settings.

“Throughout our long history,” they write, “we have been driven by excellence and innovation, and those ideals continue to inform our work today. As a global healthcare company, we are positioned to meet the needs of our customers and patients worldwide. Each day, more than 23,000 employees affirm our commitment to ‘caring for life’ and dedicate themselves to what we believe matters most in healthcare: improving patients’ quality of life.”

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Contributor News

Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2014 in the March/April 2015 issue. From January 30 to March 14, 2014, gifts were received:

In Honor Of
Bill, Jr., thirty-two years on HEN; paying it forward; and Ann Weaver’s home infusion presentation to pharmacy students

In Memory Of
Alisha Beth Hoelle, Mary Alice Kaufman, and Andrew R. Van Kleunen

Fundraisers in Honor of Feeding Tube Awareness Week
MedCo Medical Supply; Patchwork Peddler

Matching Gifts
The GE Foundation

We appreciate 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!

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 continued interest and strong commitment.

PLATINUM LEVEL PARTNERS
($70,000)
BioScrip, Inc.

GOLD MEDALLION PARTNERS
($50,000)
Coram Specialty Infusion Services
Nutrishare, Inc.
ThriveRx

SILVER CIRCLE PARTNERS
($30,000)
NPS Pharma

BRONZE STAR PARTNERS
($20,000)
Baxter Healthcare
Covidien
Fresenius Kabi USA

BENEFACTOR LEVEL PARTNERS
($10,000)
Abbott Nutrition
Home Solutions, Inc.
Kimberly-Clark
Nestlé Health Science
Walgreens Infusion Services

PATRON LEVEL PARTNERS
($5,000)
Applied Medical Technology, Inc.
Critical Care Systems, Inc.

Thank You!

Join the 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-OLEY.

Felicie Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Cetter
Jim Cowan
Rick Davis
Ann & Paul DeBacker
David & Sheila DeKold
Dale & Martha Delano
Tom Diamantidis, PharmD
Gail Egan, MS, ANP
Selma Ehrenpreis
Herb & Joyce Emich
Jerry Fickle
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Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Long
Hubert Maiden
Laura Maateme, PhD, RD, LDN,
CNSC, FADA, FASPEN
Kathleen McInnes
Michael Medoar
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
Judy Peterson, MS, RN
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Beverly Promisel
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Rosalyn & Eric Scheib Dahl
Suan & Jeffrey Schoonol
Doug Seidler, MD, FACC, CNSP
Judi Smith
Steve Swensen
Cheryl Thompson, PhD, RD, CNSC,
& Gregory A. Thompson, MD, MS
Cathy Tokarz
Eleanor & Walter Wilson
Marion & Larry Winkler
James Wittmann
Patty & Darrell Woods
Rosaline Ann & William Wu

(800) 776-OLEY • LifelineLetter — 11
Kathleen McInnes: Preserving Oley’s Future through the Horizon Society

Ensuring the survival of the Oley Foundation was an important goal for Kathleen McInnes. Oley was a critical source of information and community for herself and many others. So after her friend and support group leader, Pat Gordon, passed away, she was inspired to make a bequest to the Oley Foundation’s Horizon Society.

Kathleen was on J-tube feedings for almost two decades. She had gastroparesis, pseudo-obstruction and multiple sclerosis, but she did not let her illnesses, limited mobility, or vision prevent her from being active in Oley.

She was a Regional Coordinator and co-led the Chicago Pumpers support group. She helped plan the 2001 Oley Conference in Milwaukee, and attended several others. In addition, she and her husband Larry staffed the Oley booth at clinician meetings, and she and a fellow support group member spoke on tube feeding issues with students at a Chicago nursing school.

Kathleen was a giver. She helped Oley members who had trouble adjusting to their tube or to not eating by mouth. She had a wonderful way with words that put others at ease, and always wore a big smile on her face. For her courage and outstanding volunteer efforts, Kathleen won Oley’s Mead Johnson Enteral Award in 2001.

Larry, Kathleen’s husband, says their first Oley conference made a huge impression on them. They found a new portable pump on display whose features would allow Kathleen to have a better quality of life. “The first thing we did when we returned home was to call our home care company to request the pump.” As he recalls, it took a little convincing, but “they came around.”

Kathleen passed away in March of 2012 at the age of 67. She is survived by Larry, their two children, and daughter-in-law; and missed by the Oley community she worked so hard to build and continues to support through her bequest.

A list of Oley Foundation Horizon Society members is on page 11 of this issue. Information on the many ways you can make a lasting gift is available at www.oley.org or by calling Joan Bishop or Roslyn Dahl at (800) 776-OLEY. We hope you will join us in preserving Oley’s future for the next generation and beyond.