Choosing the Right Tube for You
Lauren Schwartz, MD

This article will discuss the placement of feeding tubes and how a doctor chooses the right tube for each patient. It includes a review of the types of tubes that are available, the indications for post-pyloric tubes that extend beyond the stomach, and, with post-pyloric tubes, the options of using a gastric tube with small bowel extension versus a tube that inserts directly into the small bowel. Management of tube dislodgement will also be discussed.

Types of Tubes
The choice of tube depends in part on whether the tube is needed on a short-term or long-term basis. Short-term tubes include the nasogastric (NG) and naso-jejunal (NJ) tubes, which go through the nose and end either in the stomach (NG) or small bowel (NJ). Tubes intended for more long-term use include the gastrostomy tube (PEG, G-tube), gastro-jejunostomy tubes (PEG-J or G-J tubes), and jejunostomy tubes (PEJ, J-tube).

Placing a Tube
Tubes can be placed in a variety of ways. They can be placed surgically by a surgeon; under x-ray guidance by an interventional radiologist; or during an endoscopic procedure by a gastroenterologist.

This article will focus on endoscopically placed tubes. An endoscope is a piece of equipment that has a long tube with a light and camera at its tip. The camera projects images onto a video screen. While a patient is under sedation, the doctor passes the endoscope through the mouth, down the throat into the upper intestinal tract.

New Connectors for Enteral Feeding Tubes
Tom Hancock, Executive Director, GEDSA

Later this year, the International Organization of Standardization (ISO) will introduce new design standards for enteral feeding tube connectors. The Global Enteral Device Supplier Association (GEDSA), an international working group of enteral feeding tube manufacturers, distributors, and suppliers, will be introducing new enteral connectors that conform to these new ISO standards. The introduction of these new connectors is an important step to improve patient safety, because the current Luer connectors have a universal design, which allows for connections between devices that were not intended to connect (for example, feeding tube to a ventilator suction catheter; feeding tube to a tracheotomy tube; blood pressure monitor to an IV line, etc.).

While tubing misconnections are less of a concern for home use, the new, safer connectors will be introduced globally. They will be for use at home, as well as in institutions, so it is important to know about the change and understand how it will impact home use.
system. While in the movies it looks like they can instantly find your location, it is neither simple nor quick. It is possible, but it requires much more time and effort than television shows portray.

The Ambulance

There is a myth that if you arrive in an ambulance you may get seen more quickly in the emergency room (ER). This is just that, a myth. Patients are triaged based on the severity of their condition.

In some larger cities, it is not uncommon to go by ambulance to the ER and get placed in the waiting room. I know I have done it with patients many times in the city where I worked. In smaller hospitals and communities you may not have to wait. But they will triage and treat based on the severity of your condition.

I have been asked about going by car versus ambulance. I propose this question to help you decide: If something happens to me on the way to the ER, will the person driving be equipped to handle it and not panic? Never, but never, drive yourself to the ER if you think something could happen while on the way there. In our EMS system, we never allow a patient to drive him- or herself to the hospital.

Whether you are tube (enterally) or IV (parenterally) fed, you should not have to disconnect from your line to be transported or IV. The emergency personnel may or may not know how to care for your own tube or line. The emergency personnel will be proactive when it comes to the care of the line(s). Do not EVER hesitate to stop and treat based on the severity of your condition.

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

911, from pg. 1

Children who are patients are more often than not an exception. We will normally allow one parent to ride with the child. Again, it depends on how the parents are interacting with the EMS personnel. If the crew feels the parent may be a hindrance to care, they do not have to allow the parent in the patient treatment area with the child. Remember their first concern is always going to be for the patient, not the family.

Communication

Communication—now there is a subject that gets confusing. It can be difficult for us, as EMS personnel, to determine if a family member is just asking questions or is a caregiver trying to help. You need to be very clear if you are the primary caregiver and have the information we may need. Due to the number of years I have been both caregiver and professional, I can usually tell after a few questions whether someone is just concerned or is a caregiver. That may not be the case with all EMS personnel. If possible, allow the caregiver to be the one to communicate with the EMS personnel. More than one person giving information can lead to confusion.

Having a prepared list of medications and medical history that we can take with us is a huge help, both to us and the ER staff. It also helps to deter any confusion. Depending on where you live, you may possibly get different EMS personnel each time you call, so be prepared to answer the same questions again. That is another reason why the prepared list will be helpful.

It’s Your Lifeline

Most EMS agencies do not offer training on HPN or G- or J-tubes. These are your “lifelines” and extreme care needs to be taken to maintain them. You are the person who maintains your line(s) and you should be proactive when it comes to the care of the line(s). Do not EVER hesitate to stop someone—even an EMS worker—who is putting your line at risk.

Gloves are mandatory in every EMS agency. I am aware of, and you should not allow an EMS worker to handle your line without them. I would like to point out that most
Oley Staff Updates

Welcome Andrea

Andrea Guidi has joined the team at Oley as the executive assistant. She is currently responsible for the HomePEN Research Prize and the Oley awards. She is also helping to coordinate the launch of the new Oley Web site, coming soon!

Andrea got her start in nutrition with an undergraduate degree at the State University of New York at Plattsburgh, and a dietetic internship at Sage Graduate School in Albany, New York. She’s provided supervision, nutrition education, and care planning in retirement and nursing home communities in Bronx, and Rye, New York.

The past thirteen years, Andrea has enjoyed being home and spending time with her three children. Andrea lives with her husband, Tony, and their family in Southborough, Massachusetts. Andrea volunteers in the school system, and enjoys running and coaching her daughter’s softball team. Andrea has run the Boston Marathon twice for charities. Since helping others has always been a priority for her, the Oley Foundation was a perfect fit. Andrea says, “I look forward to meeting new people and helping grow such a wonderful organization!”

Other Changes

We’re pleased to announce that our newsletter editor, Lisa Metzger, will now also serve as the Oley Foundation’s Director of Community Engagement. Lisa joined the Oley staff as the newsletter editor in 2007. While she’s still part-time with the Foundation, she has added more hours and taken on responsibility for our many outreach efforts. As the Director of Community Engagement, Lisa will coordinate the Oley Ambassador program and our awareness programs, such as Feeding Tube Awareness Week and HPN Awareness Week.

Intestinal Reconstructive Surgery Course for Physicians

A Master Course in Intestinal Reconstructive Newborn Surgery will be held May 6–8 at the University of Salford, Greater Manchester, UK. This intensive practical program is designed to familiarize physicians with the applications of the latest autologous bowel reconstruction techniques through live surgeries and interaction with faculty members. Speakers include doctors Adrian Bianchi, Antonino Morabito, and Basem Khalil. A full list of speakers, as well as full program and agenda, can be found at www.salford.ac.uk/spd.

Tube Talk

To make room for the abundance of critical enteral news in the rest of this newsletter, we’ve postponed Tube Talk until the next issue.

A Better Approach to Nutrition Support

At BioScrip®, we live and work by two simple words: “We’re there.”

We’re in your home, by your side, helping you get the nutrition support you require and the attention you deserve.

- Leading infusion provider with more than 30 years experience in home parenteral and enteral nutrition
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BioScrip is a national strategic partner with UnitedHealthcare® and its plans

Find out more at bioscrip.com
Insurance and Reimbursement Q&A

with Brittany Cheree Allen, Esq., The Jennifer Jaff Center

Q: What are some of the things someone on home nutrition support and/or with chronic illness should consider when selecting a health insurance policy?

A: If you have a chronic illness, the first thing you should consider is finding a health insurance policy that covers your providers and treatments. Treatment stability is very important for most conditions, so you'll want to select a plan that makes the most sense for your specific needs.

Although budget is usually the biggest concern for most people, I would urge you to consider selecting a policy that might have a higher premium if it means fewer headaches during the life of the policy because it provides better coverage.

You should also consider what kind of deductible the plan requires. Some plans on the health insurance marketplaces include deductibles that apply to all services. This means you have to meet the deductible before the plan pays anything. Most of us are used to deductibles that only apply to certain services, like hospitalizations. Make sure to note which services are subject to the deductible before you select the plan.

There are people available to help if you have questions about plans on the marketplaces. They are called Navigators and In-Person-Assisters. You can find information on help available in your state from the federal government’s marketplace Web site, HealthCare.gov.

Q: Do insurance companies make a list of in-network providers (including home care companies) available to consumers before they buy a policy? If a consumer’s provider is not in-network, what are the consumer’s options?

A: When shopping for insurance, you're usually only looking at a summary of the benefits in a plan, which won't include a full list of in-network providers. Those lists are on the insurance company's Web site. If you are already a member and want to find out if a new doctor is on the list, sign in on the member's page and search for the provider. If you aren't yet a member, the lists are typically formatted into directories where you plug in some key information—provider type, location, plan name, etc.—which can get confusing. The best solution is to call the insurance company's customer service line and ask specifically if your provider or home care company is in-network for the particular plan you are considering.

If your provider is out-of-network, you have a couple of options to consider. First, you can ask your provider for a referral to an in-network provider. If you feel comfortable switching providers, this would be the fastest/easiest option. Second, you can request an “in-network exception,” which means your out-of-network provider would be reimbursed at the same rate as an in-network provider. Contact the number on the back of your insurance card to determine where to send your request and if there are required forms. You will need to provide information that shows why none of the in-network providers would be a viable option for your treatment. This is called “capacity to provide” and your insurance company may have specific criteria you must meet. Finally, if you can't switch providers and can't get an in-network exception, you may have to pay out-of-pocket for your provider. Typically you can negotiate a discounted rate with your provider.

Q: How important is it that a provider be in-network?

A: It depends on the out-of-network coverage or lack thereof in the policy. Some plans provide out-of-network coverage at similar rates to in-network coverage. For most plans, however, there will be a higher co-pay or out-of-pocket expense for an out-of-network provider. Also, some plans have no out-of-network coverage, meaning the plan won't pay anything toward that service. Double check with your insurance policy and do the math to make the most informed decision about seeing an out-of-network provider.

Q: What can a consumer do if their nutrition support is not covered by their insurance policy? Do they have to pay out-of-pocket for supplies?

A: If you are shopping for an insurance policy, you should ask in advance if it contains an express exclusion for enteral or parenteral nutrition. If it does, then that is a factor you want to consider before enrolling in the plan. Express exclusions are hard to overcome and you will be stuck with higher out-of-pocket expenses.

If your nutritional support was previously covered under your plan, contact your insurance company and find out what changed in the policy. Are your supplies being denied because they are provided by an out-of-network provider? If so, follow the advice above regarding finding in-network providers or requesting an in-network exception.

If you are already enrolled in a plan and receive a denial for nutritional support, you can appeal. We will be providing an in-depth explanation of how to write an insurance appeal in the next issue of the newsletter.
Bidding Wars, Oley Style: Auction Items Needed

Janet Platt

The silent auction held at Oley’s annual conference has raised thousands of dollars, helping to keep all Oley programs free for you. But more importantly, it is FUN! Everyone from four to eighty-four has a blast outbidding each other by a quarter here, a dollar there. YOU are key to making it a success. What you can donate is limited only by your imagination: store bought or handmade, expensive or inexpensive—it’s all good. Highlights of past years include handmade quilts and scarves; collectibles, such as Hummel figurines; paintings; gift certificates; time-share units; concert or sporting event tickets; electronics; etc. Any energy you can give towards making this year’s event successful is much appreciated!

Encourage businesses or other organizations in your community to donate, as well. Each firm that donates services, gift cards, or merchandise to the auction (or cash to the Foundation!) will get a lot of visibility and can write off the expense as a tax deduction. Consider approaching local day spas or nail/hair salons, local sports teams, even shopping centers. Oley has a formal solicitation letter describing Oley and the auction that you can use. It is available at www.oley.org/documents/Silent_Auction_letter_2014.pdf, or call (800) 776-6539 for copies. If you’d like, Oley can send you brochures as well.

You can bring items with you to the conference, or you can ship items to Cathy in the Oley office (address on page 2). Please plan for the items to arrive by June 18. Thank you!
Connectors, from pg. 1

enteral nutrition. The new global design standards ensure that all feeding tube and feeding/administration set manufacturers will use one standard design for the connector, and it will be universally adopted into practice.

The New Design
The new connector has a unique enteral-specific design that:
• Does not allow it to be connected to any other type of connector
• Provides a locking feature that signals the appropriate connection has been made and stays in place
• Has a female connector end for administration sets and syringes that fit into the male connector end on your feeding tube

The new standards will impact syringes, as well as feeding tubes and feeding/administration sets. Enteral-specific syringes with the new standard female connector will be required to connect to feeding tubes with the new standard male connector for medication administration, flushing, and bolus feeding.

Stay Connected
The change comes as part of a larger initiative that will eventually introduce standards for connectors used in other applications, in addition to enteral nutrition. The initiative is designed to reduce tubing misconnections by making sure devices for different delivery systems are not compatible with each other. Tubing misconnections are rare, but when they do occur they can have damaging and even life-threatening outcomes.

Through our Stay Connected campaign, it is our goal that by the time the connectors reach the market, everyone who uses an enteral device is aware of the change, is prepared to transition to the safer connector, and can successfully adopt it.

Time Line
Manufacturers have worked together to develop a plan for introducing the new connectors. Transition connectors, or “adapters,” will be introduced to allow new feeding/administration sets and syringes to connect to your existing g- and/or j-tube. Feeding/administration sets with these adapters will start to be distributed in the fourth quarter of 2014. This will minimize any disruption to consumers and allow you to use the feeding tubes and feeding/administration sets you have on hand.

The adapter will allow compatibility with your existing feeding tubes for the introduction period and help synchronize the introduction of the new connector system. Eventually, these adapters will be phased out as feeding/administration sets, syringes, and feeding tubes with the new connector all become readily available.

Timing of the Transition to New Connectors

Fourth quarter 2014
Customers currently ordering sets with the stepped/Christmas tree connector will receive transition feeding/administration sets.

First quarter 2015
Syringes used for flushing and bolus will be available with the new connector.

Second quarter 2015
New enteral feeding tubes with ISO standard connector will be available.

January 2016
Transition to new ISO standard connectors will be complete. At this point, the current universal Luer connector will no longer be available.

How the Connectors Will Change

The new design standard impacts the entire enteral feeding system

Image courtesy of GEDSA
I ran my first marathon in Memphis, Tennessee, in December 2008. My friend and I had trained for the race together and after finishing, we couldn’t wait to run the next one. We decided it would be fun to run a marathon in each of the fifty states. In 2009 and 2010, we ran races in Alabama, Arkansas, Georgia, Missouri, and South Dakota.

In 2011, I got very sick. I vomited every time I ate or drank. I was diagnosed with idiopathic gastroparesis. Facing weight loss and malnutrition, I had to start IV hydration and then home parenteral nutrition (HPN). After taking some time off from running, I finally got back into it. Last year, I finished two half-marathons.

I have been apprehensive about whether I could maintain hydration and nutrition during a full marathon. After a lot of brainstorming and help from the pharmacists and nurses at my home infusion company, however, I have a plan, and I will be running the San Francisco Marathon July 27, 2014.

I have decided to devote my marathon training and race to raise awareness for HPN and to raise money for the Oley Foundation. I would like to invite other HPN consumers, Oley members, or caregivers that are runners to join me for the race. It would be great to have an Oley team! If you are not much of a runner but live in the San Francisco area, it would be great if you could come out and cheer me (us!) on!

For more information, contact me at emtillman@gmail.com or Joan Bishop at the Oley offices (800-776-6539 or bishopj@mail.amc.edu). Emma has set up a fundraising page through the San Francisco Marathon Web site, to benefit the Oley Foundation. To donate, go to www.crowdrise.com/HPNawareness. You can also donate directly to the Oley Foundation (by phone, mail, or at www.oley.org). Please indicate that it’s in honor of Emma’s run.

Emma, an HPN Consumer, rehydrating after running a half-marathon
2014 Oley Awards

Nominate Someone Who Inspires You!

The six awards Oley presents this year recognize those in our community who have earned our respect, inspired us, and taught us. We are pleased to have added the Innovator/Advocate award! Nominate someone today, following the criteria listed below. We’ve provided a form you can use as a guideline when submitting your nomination(s). Nominations must be received by March 18, 2014.

Awards will be presented at the 2014 Oley Consumer/Clinician Conference to be held June 23–27 at the Renaissance Orlando at SeaWorld in Florida, and the awardees will be spotlighted in the LifelineLetter. Recognition is given to all nominees.

The Awards and Criteria
Innovator/Advocate Award—NEW!
In honor of BioScrip, Platinum Partner
• HPEN consumer or caregiver
• Any age
• Sets an example by promoting innovation in nutrition therapy, or by advocating for themselves or someone in their care
• Winner receives a partial travel grant to the Oley annual conference

LifelineLetter Award, HPN
In honor of Nutrishare, Inc., Gold Medallion Partner
• Home parenteral (HPN) consumer or caregiver for 5 years or longer
• 19 years of age or older
• Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HPN
• Winner receives a partial travel grant to the Oley annual conference

LifelineLetter Award, HEN
Sponsored by Abbott Nutrition, Benefactor Level Partner
• Home enteral (HEN) consumer or caregiver for 5 years or longer
• 19 years of age or older
• Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN
• Winner receives a partial travel grant to the Oley annual conference

Child of the Year Award
In honor of ThriveRx, Gold Medallion Partner
• HPEN consumer for 1 year or longer
• 18 years of age or younger
• Shows a positive attitude in dealing with illness and therapy which encourages and inspires others
• Winner receives a partial travel grant to the Oley annual conference

Celebration of Life Award
In honor of Coram Specialty Infusion Services, Gold Medallion Partner
• HPEN consumer for 3 years or longer
• Any age
• Lives life to the fullest: traveling, fishing, gardening, volunteering, attending school, spending time with family, etc.
• Winner receives a partial travel grant to the Oley annual conference

Nan Couts Award for the Ultimate Volunteer
Inspired by Judy Peterson, RN, MS
• Clinician (physician, nurse, dietitian, etc.) practicing in the field of HPEN or related field (psychology, interventional radiology, pain management, etc.)
• Demonstrates a willingness to give of themselves, above and beyond their regular work hours, to educate, empower, and improve the quality of life for HPEN consumers

2014 Oley Award Nomination

1. Provide the following information:
I am pleased to nominate the following individual for the 2014:

☐ Innovator/Advocate Award
☐ LifelineLetter Award, HPN
☐ LifelineLetter Award, HEN
☐ Child of the Year Award
☐ Celebration of Life Award
☐ Nan Couts Award for the Ultimate Volunteer

Nominee’s name: ___________________________________
Age: ______ Daytime Phone: ( ______ ) ______ - ________
E-mail: _______________________________________
Primary diagnosis: __________________________________
No. years on HPEN ______

Your name: _______________________________________
Daytime Phone: ( ______ ) _______ - __________
E-mail: _______________________________________

2. Tell us why you are nominating this person.
Cite specific examples of how the nominee meets the award criteria. Please limit length to one page (attach).

3. Submit nomination by March 18 to:
The Oley Foundation
43 New Scotland Ave., MC-28
Albany Medical Center
Albany, NY 12208
Fax (518) 262-5528
E-mail harrinc@mail.amc.edu

Questions? Call (800) 776-OLEY
In Memoriam: Alisha Hoelle

It is with a heavy heart that we share the news of Alisha (Alicia) Hoelle's death in December. The Oley community grieves and holds her parents, Rose and Jeff, close in thought and prayer. The Hoelles have had a strong presence at Oley’s annual conferences. Attendees have always been welcomed by Jeff at the registration desk, and Rose and Alisha, Oley Ambassadors (formerly Regional Coordinators), have been equally warm and welcoming. Alisha and Rose always contributed greatly as we gathered to learn and share ideas.

Some may recall Alisha choosing to attend the Oley conference instead of her high school graduation. We “graduated” her after the morning keynote address (see right)!

Serving as Ambassadors, Rose and Alisha connected to countless others, meeting them with open arms and an eagerness to help, often while they wrestled with their own challenges. The combination of the adult and parent perspectives, along with Alisha’s having “grown up” on home parenteral and enteral nutrition, was more helpful than words can describe, and many benefited greatly as Rose and Alisha shared their experiences. They have helped countless others adjust and live fuller lives.

We wish the Hoelles much strength moving forward, and hope they find comfort in knowing that our community grieves with them.

Carol Smith, RN, PhD, and her research team at the University of Kansas Medical Center are looking for home parenteral nutrition (HPN) consumers and their family members to participate in a study using iPads to connect with other HPN families and health care professionals. They have completed tests with the first set of thirty-one families and are starting testing with another group of thirty-one families.

The study does not involve any changes to clinical care. It tests health care use of an iPad loaned to HPN families. The study lasts twelve months; you will be asked to complete online surveys before the iPad is loaned, during the iPad loan period (about six months), and once after the iPad is returned. The iPad has a prepaid unlimited data plan, so there are no costs to families for its use.

If you or your family’s HPN consumer (13 years or older) and at least one (but preferably all) family member(s) would be interested in this study, please complete the short and securely protected form at https://redcap.kumc.edu/surveys/?s=4CrygR. Within the online form are consent forms that provide additional study details. If you have questions or need additional information, please feel free to contact Donna at dyadrich@kumc.edu.

The study is funded by the National Institute of Biomedical Imaging and Bioengineering, National Institutes of Health.
Feeding Tubes, from pg. 1

This allows the doctor to see the inside of the esophagus, stomach, and small intestine, and to pass a tube safely into the intestinal tract.

NG- and NJ-Tubes

Short-term tubes include those that pass down the nose and into the stomach (NG-tube) or into the small intestine (NJ-tube). These tubes must be removed after four to six weeks to avoid complications, such as sinusitis or tissue breakdown within the nasal cavity.

An NG-tube can be placed at the bedside. An NJ-tube, however, is typically placed under endoscopic guidance because the tube must pass beyond the stomach outlet and into the small bowel. Several approaches can be used to position the NJ-tube.

One approach entails placing an NG-tube and then inserting an endoscope along with a forceps or snare device. The doctor will use the forceps to grasp the tube and guide it down into the small bowel with the endoscope. Another approach is to put a guide wire into the small bowel through a channel in the endoscope. The wire remains in place as the endoscope is withdrawn, a tube is passed over the wire, and then the wire is removed while the tube stays in place. A final approach is to pass an endoscope into the small bowel and feed a small caliber (3 mm) NJ-tube through the endoscope channel into the small bowel. The doctor then gradually advances the tube into the small bowel as the endoscope is withdrawn, leaving only the tube in place.

You may be wondering how a tube that is placed endoscopically through the mouth can come out through the nose. Once the tube is in place, the doctor transfers the tube from the mouth up the nose with a special device. Sometimes a pediatric scope, which is very small, allows an alternative. This scope is a little thicker than spaghetti, and the doctor can pass it down the nose instead of going through the mouth as in a normal endoscopic exam. In this manner, the tube can be put right into the nasal passage.

Long-Term Tubes

Long-term feeding tubes can remain in place as long as they are needed. These tubes can be divided into two categories: pre-pyloric and post-pyloric tubes. The pylorus is the stomach's outlet into the small intestine. A pre-pyloric tube refers to a tube extending into the stomach, and a post-pyloric tube is one that extends through the stomach into the small intestine. The two types of post-pyloric tubes include the gastro-jejunostomy tube and the jejunostomy tube.

Gastrostomy Tube

A gastrostomy tube is a tube that passes through the abdominal wall into the stomach. Often, the initial gastrostomy tube is placed endoscopically by a gastroenterologist. A tube placed this way is called a percutaneous endoscopic gastrostomy, or PEG, tube. To place a PEG tube, the doctor advances an endoscope down the patient's throat into the stomach. Once the endoscope is in the stomach, its light can be seen on the surface of the patient's abdomen. The doctor will then push on that spot while looking at the image of the inside of the stomach projected by the endoscope. If he or she can see that the stomach wall is compressed with that motion, the doctor knows this is where the tube should be placed.

Once this site is identified, the doctor sterilizes the skin, injects numbing medicine, and makes a small (1 cm) incision. The tube is then pulled through the stomach and out the abdominal wall. The tube is held in place on the inside by a plastic bolster or a water-filled balloon bolster, and on the outside by a plastic disk that sits on the surface of the abdomen. (See figure 1.)

Gastro-jejunostomy Tube

A gastro-jejunostomy tube refers to a gastrostomy tube with an extension that goes into the small bowel. When placed endoscopically, it is called a PEG-J tube or a JET-PEG, which stands for “jejunal extension through a PEG.” A PEG-J is put in by placing a standard PEG tube (as described above), and then inserting a smaller-caliber tube through the PEG. An instrument is then advanced through a channel in the endoscope, and the doctor will use it to grasp the inner tube and carry it into the small bowel with the endoscope. The doctor then releases the inner tube and carefully withdraws the endoscope, leaving the tube in place. (See figure 2.)

Jejunostomy Tube

A jejunostomy tube (J-tube) is a tube that is inserted directly into the jejunum, which is a portion of the small intestine.

The endoscopic approach to placement is similar to the one used for the PEG tube. The only difference is that the doctor uses a longer endoscope to enter into the small intestine. Once the endoscope is in the small intestine, the doctor will once again look for the light shining onto the surface of the abdominal wall and look for the indentation into the small intestine wall when he or she presses externally on that spot. The doctor will cleanse and numb the skin, make an incision, and pass the tube through.

When to Use a Post-Pyloric Tube

A post-pyloric tube should be considered when there is a contraindication to placing the tube directly into the stomach due to prior surgery; or when there is slow stomach emptying, due either to a mechanical blockage of the stomach outlet or to sluggish stomach motility. Examples of surgeries that make placement of a post-pyloric tube preferable or necessary include prior removal of part or all of the stomach (“gastrectomy”) or esophageal surgery involving removal of part of the esophagus and repositioning of the stomach into the chest to take its place (“esophagectomy with gastric pull-up”). In these situations, a PEG cannot be placed because the stomach is too small, absent, or sitting in the chest cavity rather than the abdomen.
Patients with slow stomach emptying due to impaired motility ("gastroparesis") should also be considered for a post-pyloric tube since they cannot tolerate infusion of feeds into the stomach without experiencing significant discomfort, reflux, or early satiety. Similarly, if the stomach outlet is narrowed or mechanically blocked, feeding into the intestine beyond the stomach is necessary.

A J-tube can prevent aspiration of tube feeds in patients who have delayed gastric emptying. Importantly, J-tubes do not protect a patient from aspiration of oral secretions. This form of aspiration is common in the elderly and patients with a weak swallow mechanism or impaired mental status.

**PEG-J or JET-PEG versus PEJ**

The decision to use a gastrostomy tube with small bowel extension tube (PEG-J or JET-PEG) versus a tube that goes directly into the small bowel (a PEJ or surgical jejunostomy) is based on a variety of factors. The first consideration is whether the patient already has an existing PEG tube. Some patients with PEG tubes discover after the fact that they cannot tolerate feeds into the stomach and they need a post-pyloric tube. In such patients, it is possible to convert the PEG to a PEG-J and avoid placing a completely new tube at an alternative site on the abdominal wall (which would also require a new incision).

A second consideration is whether a patient requires a tube in both the stomach and the small intestine. This scenario is common for patients with severe gastroparesis, who need a tube in the stomach to drain gastric juice that can build up and cause vomiting, and a tube in the small intestine for delivery of feeds. In such a patient, specially designed PEG-J systems that have an opening in the stomach portion of the tube and a second opening in the small bowel portion of the tube can be used to meet this dual function. Alternatively, these patients can undergo placement of two separate tubes, a PEG and a PEJ.

Other factors that should be considered when deciding between a PEG-J and PEJ are ease of placement and associated morbidity. PEG-J tubes can be challenging to place and maintain because the small bowel extension can either fall back into the stomach or become clogged due to its small caliber. On account of these problems, repeat procedures to reposition or replace the extension tube are common.

In one study comparing PEG-J and PEJ re-intervention rates over a six-month period, 56 percent of patients with the PEG-J required re-intervention compared with 13.5 percent of patients with a PEJ. Based on these numbers, it seems that a direct PEJ is the better choice. That said, it can sometimes be difficult to find a gastroenterologist who is experienced in PEJ placement. Although the PEJ tube has been around since the mid-1990s and the principles of placement are the same as the PEG, not all gastroenterologists are comfortable performing the procedure. In such instances, a patient might be referred for placement of a surgical jejunostomy instead.

**Tube Dislodgement**

Sometimes a feeding tube can fall out. This can occur when there is a traumatic tug on the tube or if the bolster holding the tube inside the stomach or intestine is a fluid-filled balloon that has degraded. When a tube falls out, the next course of action will depend on how long the tube has been in place.

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**Feeding Tubes**, from pg. 11

If the tube has been present for four or more weeks, a mature tract has probably formed between the stomach and the abdominal wall. This means that the stomach (at the site of the tube) has adhered to the internal abdominal wall and will remain adhered even if the tube is removed. This adherence seals the hole in the stomach, preventing gastric contents from leaking into the abdominal cavity. It also keeps the opening in the stomach in a fixed location so a new tube can be easily placed into the tract at the bedside. In this case, tube replacement should be done as soon as possible, since the opening in the stomach or small bowel can close within twenty-four hours of tube dislodgement.

Oftentimes a Foley catheter is used as a replacement tube in the emergency room (ER) when a standard replacement device is not available. The Foley tube can be used for feeding (or drainage) until a standard PEG replacement can be placed. X-ray confirmation of tube position is advised when a dislodged tube is replaced.

I always make sure the patient has a replacement device at home so that if the tube comes out, he or she can bring the new device to my office or the ER for re-insertion. I also offer patients the option of learning how to replace the tube themselves, though many are apprehensive and prefer to come back to the office. I replace tubes with an internal balloon bumper every four months, because the integrity of the balloon decreases over time.

If a PEG tube has been in place for less than four weeks and the stomach has not adhered to the abdominal wall, the stomach will fall away from the wall when the tube is removed, leaving the hole in the stomach uncovered. The unsealed hole places the patient at risk for leakage into the abdominal cavity and associated infection. Further, a new tube cannot be safely passed back through the abdominal incision and into the stomach if the stomach hasn’t adhered to the wall. It could result in the tip of the tube sitting in the abdominal cavity rather than in the stomach. Instead, the patient should be hospitalized, started on antibiotics, and observed for infectious complications; a surgical intervention is sometimes required.

These principles apply to dislodged G-tubes, PEG tubes, PEJ tubes, and PEG-J tubes. The one additional factor that needs to be addressed with the PEG-J is replacement of the small bowel extension, which can be done endoscopically or under X-ray guidance.

**Low-profile Devices**

If a patient requires a long-term PEG or PEJ, he or she may be a candidate for a low-profile device (“gastrostomy button”) when it is time to replace the first tube. Unlike the standard G- or J-tube, the low-profile device rests flat on the skin surface. The user connects extension tubing to the low-profile device during feeds. The device consists of a short tube (1 to 5 cm) with an inflatable balloon or a “mushroom” bolster on one end (inside the stomach or intestine) and a capped feeding port on the other end.

Although the low-profile device is often more desirable, it is usually not placed as the initial tube in adults. Instead, a standard tube is placed. It is removed two to three months later (after the tract has matured) and replaced with a low-profile device. This approach is preferred because it is difficult to estimate the distance between the patient’s stomach and the outside of the abdominal wall. Having the standard tube in place first allows us to make this measurement and order the proper size low-profile tube. Proper fit is important because if the tube is too tight it can create an ulcer in the stomach and lead to tube dislodgement, and if the tube is too loose it can result in gastric contents leaking onto the skin surface.

**Summary**

- Feeding tubes can be placed surgically, endoscopically, or radiographically. In most hospitals, the endoscopic approach is first line, since it is minimally invasive and readily available.
- When a tube is placed endoscopically through the skin, it is termed a percutaneous endoscopic gastrostomy (PEG), -jejunostomy (PEJ), or -gastro-jejunostomy (PEG-J or JET-PEG).
- Pre-pyloric tubes terminate in the stomach while post-pyloric tubes terminate in the small intestine. Post-pyloric tubes are indicated when there has been prior stomach surgery that precludes placement of a gastrostomy tube, and when a patient cannot tolerate tube feeding into the stomach due to impaired stomach emptying.
- The choice of a PEJ versus a PEG-J depends on a variety of factors, including the presence of a pre-existing PEG, the need for a single tube to both drain the stomach and feed the intestine, and the expertise available for tube placement.
- When a single tube for feeding into the small bowel is needed, a PEJ is often preferred since the small bowel extension tube of the PEG-J tends to fall back into the stomach or become clogged.
- Low-profile devices should be considered as a replacement tube in patients requiring long-term enteral access.
- If a tube becomes dislodged, a patient should seek immediate medical attention. A long standing tube can be easily replaced at the bedside, but this must be done as soon as possible to keep the tract from closing. A new tube (less than four weeks old) cannot be replaced at the bedside and dislodgement could lead to more serious complications.

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**Table 1. Types of tubes**

**Short-Term Tubes**

- naso-enteric tubes
  - naso-gastric (NG)
  - naso-jejunal (NJ)

**Long-Term Tubes**

- pre-pyloric tubes
  - gastrostomy tube (G-tube)
  - percutaneous endoscopic gastrostomy tube (PEG-tube)
  - low-profile device
    - fluid-filled balloon bolster
    - mushroom bolster
- post-pyloric tubes
  - gastro-jejunostomy tube (GJ-tube)
  - jejunostomy tube (J-tube)
  - PEG-J
  - PEJ
  - JET-PEG tube
  - G-JET tube
  - low-profile device
EMS agencies do not supply or use sterile gloves. If you normally use sterile gloves or technique for your line, be sure to tell that to the EMS personnel and tell them you will handle anything involving your line.

**Thinking Ahead**

After we called the EMS unit one evening, it became very apparent to me they were confused by Tammi’s HPN running. While I knew the crew and was very comfortable with them taking care of Tammi, I was concerned that if something happened to the line, would they know what to do? After we explained the whole process they seemed to be better with it, but it made me think about what I could do to be better prepared.

If I was at home and something happened, I would have everything I needed. But what if we were traveling, at someone else’s home, or already in the ambulance? After that incident I thought what I would have needed with me at that time. So the “grab-and-go bag” came about.

**Grab-and-go Bag**

As I was creating our grab-and-go bag, I was thinking what I would need to have on hand and for how long for emergency situations. I decided I would place in the bag at least two of everything we would ever use per day or infusion period. The exception is obviously Tammi’s HPN and vitamins, which must be kept refrigerated.

I included anything I could anticipate ever using. Syringes, alcohol preps, extra line caps, and catheters are just a few of the items. For your bag, you should include anything you think you may need. I included what I thought would get us through for a week. If your pump is rechargeable, do not forget to include whatever batteries it requires as a backup.

I have also uploaded onto a flash drive all of Tammi’s medication information, recent lab values, power of attorney (POA) paperwork, and medical history. Most medical facilities can print it for their patient records. [Go to www.oley.org or call (800) 776-OLEY, for a Travel and Hospitalization Packet.]

This bag could also be used for in-hospital stays. Once when Tammi was admitted, the concentration of heparin they were using was different than what we normally used, so when we arrived home, I added our heparin to the bag.

IV fluids can be kept in the bag for quite some time. After discussing my concerns with our healthcare company pharmacist, he informed me Tammi would probably do fine on IV fluid (lactated Ringer’s solution for her) in the extreme event something happened and we could not get her HPN. This is specific for Tammi only, and you should discuss with your doctor or pharmacist whether in an extreme emergency this would work for you.

**Extreme Weather**

While we’re on the topic of extremes, we live in the Midwest, where we see the extremes of all weather it would seem. Snowstorms, ice storms, tornados, severe thunderstorms, extreme cold and extreme heat are all common. We had a low of minus 24 degrees in January and it is not uncommon to have temperatures of ninety-plus in the summer.

Power outages are also common. If there was an extended power outage would you be prepared? Do you have enough batteries to run your pump without electricity? What if you had to leave suddenly? For those not familiar with tornados, you may only have minutes to take cover. Same for a wildfire. If that happened, would you be ready to go?

In wildfire firefighting, we use the saying “ready, set, go.” The same would apply here. Having the grab-and-go bag ready is a must. I can grab that and Tammi’s PN as we are going out the door.

Do you have an alternative place to ship supplies to in the event you must vacate quickly and cannot return home for an extended period of time? Do you have copies of your prescriptions in the event they must be replaced in an emergency? Talk with your family, home care provider, doctor, and insurance company to make sure you know what you will need in an emergency.

**Conclusion**

The Boy Scout motto probably says it all: “Be Prepared.” While none of us can predict when an emergency will strike, we can do our best to be prepared for it. Being prepared will allow a smoother transition back to normal and will reduce some of the stress involved when an emergency strikes. It will also help to ensure a positive outcome.

My homework assignment to you today is: Start thinking now about what you can do if you hear, “911: What is your emergency?”
Donor Profile, Jim Lacy, RN, BSN, CRNI, VA-BC

Jim found out about the Oley Foundation through a patient presentation at a clinical meeting. As he put it, “It knocked my socks off! I had many years experience in home infusion, but I learned so much from the patient perspective, [including] the absolute importance for clinicians to present all options to the patient and to involve them in the decision making process.”

As Jim got more involved, he was impressed with Oley’s work and began donating regularly. “I give an automatic monthly gift to Oley because it’s easy. I don’t have to think about it.” Adding, “And by doing it monthly, it feels like a lot less than it would as one check or credit card payment.”

Jim works in the nutrition support industry now, but says he finds his dealings with Oley just as important as ever. “We [in industry] make too many assumptions about the products and services we provide. Contact with patients puts my feet back on the ground.”

In addition to his financial support, Jim has been generous to Oley with his time and expertise. While serving as an Oley Trustee, Jim provided strategic input, and he has helped resolve medical questions for Oley staff.

Highlights from A.S.P.E.N.’s Clinical Nutrition Week

Clinical Nutrition Week is the annual conference of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). It’s an exciting week, where Oley staff is able to learn the latest about topics that have a direct impact on you, home parenteral and enteral (HPEN) consumers. We heard presentations on cutting-edge topics such as intestinal regeneration and telehealth, as well as on familiar topics such as catheter-related infections, tube-feeding complications, and quality of life on home nutrition support. Watch for some of these topics on the Oley conference agenda!

While at our booth in the exhibit hall, Oley staff and volunteers were able to interact with hundreds of nutrition support professionals. We introduced our new tagline—now part of the Oley logo—at our booth, and Fresenius Kabi helped us celebrate with a cake (big enough to serve 100+). Clinical Nutrition Week is a vital learning and networking opportunity.

Another highlight of Clinical Nutrition Week is the presentation of the Lyn Howard Nutrition Support Consumer Advocacy Award, which went to Ann Weaver, an Oley member and former Oley Regional Coordinator. Ann has worked hard to bring attention to the problems drug shortages are causing, particularly for home parenteral nutrition consumers. Last year, her efforts included communicating with elected and appointed government officials, starting a petition on Change.org (and gathering over 3,700 signatures), and spreading information about the shortages—and their effects—widely through social media and other outlets.

Our congratulations to Ann, and our thanks for all she is doing. We encourage you to honor her by signing the petition on Change.org (search for “Senator Tom Harkin, IA, and Representative Fred Upton, MI, Compel FDA to End IV Drug Shortages”).
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 2013 in the March/April 2014 issue. From November 2, 2013, through January 29, 2014, gifts were received:

In Honor of
32 years on HPN and 30 years with Oley; all fellow consumers and families; Julie Andolina; Rebecca and Daniel Appel; Patricia Brown; Mike Christenson; Colorado State Infusion; Mary Ellen Costa; Frances Culp, eight years on HPEN; Roslyn Dahl; Rick Davis; Jackson Merril Dietel's birthday; Angel Fravel; Patricia Grasso; Dr. Lyn Howard; Barbara Klingler; Mike, Jenny, and Katie Lunsford; John Mahalchak; Jennifer Mason; Dean May's birthday; Michael Medwar; Jonathan Nelson; Ryan Peot's 16 years of HPN; Dr. Ellen Pierce and Mr. Chris Ericksen's 17th wedding anniversary; Rachel Schten; J. T. Sherrow; Maurice Shil's 99th birthday; Tanner Shuman, 17 years on HPEN, 10 years off HPN; Bertha Soto; the ThriveRx team; the love and caregiving of Kay and Roger Tims; Tegan Watkins; Molly Westmoreland; Don Young; and Kim Zeller

In Memory of
Alma Louise Anderson; Nancy Backinger; Dwight Bastian; Doris Baumgartner; June Bodden; Evelyn Brown; Ann DeBarbieri; Jeff Dutton; Susan Herman; Alisha Beth Hoelle; Joshua Horz; Joyce Hydorn; Frank Jones; James H. Jones; Larry Karacki; Mary Alice Kaufman; Shirley Klein; Robin Lang; Libby Levin, on her birthday; Leslie Noyes; Clarence “Oley” Oldenburg; Eleanor Orkis; Benjamin Pastore; Ruth Rosenblatt; Kenneth Rosenhek; Bekki Schreiner; Josh Shapiro; Sallie Simpson; Paula Southwick; Bob Sweet; Terry Williams; and Calli Vaughn

Matching Gift
Jones Lang LaSalle

Fundraisers
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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 Pharmaceuticals

BRONZE STAR PARTNERS
($20,000)
Baxter Healthcare
Fresenius Kabi USA
Moog Medical Devices Group

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

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

Thank You!
29th Annual Oley Conference Heads to Orlando This June!

Where: Renaissance Orlando at SeaWorld
When: June 23–27
Room rate: $135/night for single or double, available for three days before and after the conference. To secure this rate, go to https://re-sweb.passkey.com/go/TheOleyFoundation or call (800) 266-9432 and mention you are with the Oley Foundation Annual Meeting. Cut-off date is June 2. Reserve now! Rooms will sell out.

Topics
Planning is under way for the sessions, and ideas on topics and speakers are welcome. Please send any thoughts on what you like to see covered and recommendations for speakers to Joan Bishop at bishop@mail.amc.edu.

Travel Grants Available
If you’ve never been to an Oley annual conference, we encourage you to apply for a first-time attendee travel grant. Submit two paragraphs describing how you believe attending the conference will affect your life, and how you might share information learned at the conference with consumers and/or clinicians back home. Determination will be made by May 16, allowing recipients plenty of time to make travel plans. Send to harrinc@mail.amc.edu or The Oley Foundation, 43 New Scotland Ave., MC-28, Albany Medical Center, Albany, NY 12208. Travel must be completed, and receipts received by Oley, before reimbursement can be made.

Watch for the registration brochure. Updates will be posted on www.oleany.org and circulated via e-blasts. Keep us posted with your e-mail address changes!

Planning Meeting
A conference planning meeting will be held at the Renaissance Orlando at SeaWorld in Orlando on March 12, 3:30 to 6:00 p.m. Everyone is welcome. Bring your ideas! R.S.V.P. to bishop@mail.amc.edu or call (800) 776-6539.

2014 Regional Meetings
Oley has plans to host several regional meetings throughout this year to bring information and networking opportunities to more members, closer to your homes. Areas being considered are: Atlanta, Georgia; Chicago, Illinois; Columbus/Cleveland or Cincinnati, Ohio; New York City, New York (tentative date, April 11); Providence, Rhode Island; and San Francisco, California (tentative date, July 26). We’ll post updates on www.oley.org and circulate invitations by e-mail and the Post Office, as well as in future issues of the LifelineLetter. (Another reason to keep your addresses current with Oley!) Note: If you are in the areas listed and would like to suggest topics or speakers and recommend meeting sites to be considered, please contact Joan at bishopj@mail.amc.edu.