Eric’s Story: Transplant

Eric James Thatcher

Diagnosed with Crohn’s disease when he was in his teens, Eric has undergone several surgeries and as a result had short bowel syndrome, until October 2016, when he had an intestinal transplant. Eric has shared his story with us from his early years through the transplant process. Because of space limitations, we have posted the full story on our website, at oley.org/ettransplant, and share only the latter part, up to spring 2017, here. If you’d don’t have access to the internet and want us to mail you a copy of “part one,” please call us at (518) 262-5079. It is a great read!

Many people use their calendars to track social events, but living with Crohn’s disease for most of my life, my calendar has always been filled with doctor visits and medical testing dates. It seems almost every hour has been dedicated to changing my colostomy bag, taking shots, swallowing pills, or setting up to run my home parenteral nutrition (HPN), which is a project unto itself.

Appointments
My first appointment in 2015 was with my GI doctor. I was receiving HPN, so they were monitoring my liver functions. The CAT scan showed a suspicious spot on my left kidney. Further testing, including a biopsy, revealed I had a cancerous tumor.

After consulting with several specialists (all with different opinions on the best course of action), in June I had half of my left kidney removed at a hospital in nearby Massachusetts. The surgeon was confident all cancerous cells had been removed and I would not require chemotherapy. My parents and I were relieved.

Medicare Coverage for HPN...An Oxymoron?
Penny Allen, RD, CNSC, National Director, Nutrition Support, BriovaRx Infusion Services (formerly AxelaCare)

This article is adapted and used with permission from Allen P. Medicare Coverage for Home Parenteral Nutrition—An Oxymoron? Part I, Practical Gastroenterology. 2016;(12)34. Much of the information is directed at healthcare professionals. However, there is a lot of information here that may apply to you if you are on home enteral and/or parenteral nutrition (and Medicare) now, and/or may be on home parenteral nutrition (and Medicare) in the future. We hope you will find it useful. Additional tables are available online or by calling (518) 262-5079.

Physicians face increasing pressure to discharge patients earlier from the acute care setting. If there is any possibility that a patient* (see note page 14) may require home parenteral nutrition (HPN) post-discharge, the process of clearing insurance to determine coverage for HPN should be started immediately so the health care team and the patient are aware of what is required. This should be the case for any insurance plan a patient may have.
Transplant, from pg. 1

After surgery, though, I didn’t have the energy to get myself out of bed, even to use the bathroom. I voided into a urinal and my dad riged up a system for me to empty my colostomy bag without having to get up. I was tired of being sick and bedridden. My condition was taking a toll on me, and on my parents as well. We had hoped for a favorable outcome following this surgery.

My dad decided there must be a medical approach that could improve my quality of life. He searched the internet for information on Crohn’s disease. Many months earlier we had received a newsletter from the Oley Foundation. One of the articles in it mentioned a medical center that, it said, was one of only a few in the country performing intestinal transplants.

My dad found an email address for the clinical coordinator of that transplant center and sent her a copy of my story, along with a desperate plea for someone to contact him. Within hours they responded, saying they were confident they could help me.

The Transplant Center

Before our first appointment with the transplant team, which was scheduled for July, I had to obtain medical records from my primary care provider (PCP), GI doctor, the medical team overseeing my HPN, and the primary care provider (PCP), GI doctor, the medical team overseeing my HPN, and the

Financial stability is critical, too, as many of the costs associated with the procedure are not covered by health insurance, such as housing near the center for one of my parents during my eight- to ten-week recovery period, transportation for follow-up visits, and possibly out-of-pocket expenses for anti-rejection drugs. During the first year following surgery, we were told the costs for medications could be as high as $40,000.

Our visit lasted several hours, and I went home with a list of things I needed to accomplish before my next visit, when the surgeon would go over the details. I felt fear, excitement, and doubt about whether I would be viewed as a candidate. By the time we arrived home, it had been a seventeen-hour day. We were physically and emotionally exhausted.

Next Steps Toward Transplant

Four weeks later, we made our second trip to the center. This trip was less harried, though in the end, it was still a fourteen-hour day. The nurse practitioners told us that a transplant of this nature is life-altering for the patient, and also for the patient’s family. First is the twelve-hour surgery, then the uncertainty over whether the organs would be rejected. There is approximately a 20 percent mortality rate—meaning one out of every five patients undergoing a small bowel transplant could die within the first year.

My heart skipped a beat when they discussed the donor process. Reality strikes home when you think how an individual or family has made a courageous and unselfish decision to help save the life of a total stranger.

All candidates must go through extensive pre-testing and psychological profiling, and all of their medical records must be reviewed (twenty plus years’ worth, in my case) by a committee of medical experts.

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Tube Talk
Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@mail.amc.edu. Information shared in this column represents the experience of the individual and should not imply endorsement by Oley. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.

PEG Feeding Stand
When my father got a percutaneous endoscopic gastrostomy (PEG) tube, I designed this device so he could feed himself. This way, he is not dependent on his wife or other caregivers. The device is simple equipment from any chemistry class lab in the nation: a pole stand and two burette clamps. They can be purchased at Amazon.com (www.amazon.com/American-Educational-Stamped-Support-Resistant/dp/B00657N7TS and www.amazon.com/gp/product/B00AWS3RGY).*

My father can use the stand with a long tube (as with an extension set), and without. When he uses it without, he turns the base of the stand, and lowers the clamps. When you do this, it is a good idea to add some weight to the base.

I hope this helps inspire people.
—Donald M. Erway, derway@earthlink.net

*Editor's note: If you do purchase through Amazon, don’t forget Amazon will make a donation to the Oley Foundation if you sign on through smile.amazon.com and designate the Oley Foundation as your chosen charity.

FDA Listens and Learns
The Food and Drug Administration (FDA) wants to understand what people in the tube-feeding community do, so they can understand individual needs and concerns, and identify unmet needs. To help with this effort and at the FDA’s request, the Oley Foundation and Feeding Tube Awareness Foundation invited enteral nutrition consumers and caregivers to the FDA offices on May 22, where they spent the day discussing and demonstrating for the FDA exactly what is involved in tube feeding at home—from blending their own foods, to administering medications, etc. The Oley Foundation would like to thank those who came and shared their tube-feeding practices.

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

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

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

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

New Oley Board Members

We are pleased to introduce our new treasurer, Jim Senese, BS Pharm, MS, and Joy McVey Hugick. Both joined the Oley board last fall.

Jim Senese is actually rejoining our board, having served as Oley’s Treasurer and as a board member from 1997 to 2001. In 2014, Jim became a cancer survivor and a short-term (nine months) enteral nutrition consumer. He has over thirty-five years experience in the medical field with a broad background in practice management, operations, and medical sales.

Jim is currently Director of Network Development for the Oncology Circle (a division of Flatiron Health), a data-sharing collaborative of best-in-class oncology practices, dedicated to clinical and operational excellence through the scientific collection and use of data. He is the principal author of the Drug Acquisition Cost Index, a resource for drug cost information, and a contributor to the National Practice Benchmark Report, which is published in the American Society of Clinical Oncology’s Journal of Oncology Practice.

Prior to joining Flatiron, Jim was a Regional Vice President for US Oncology. He has also held various positions with Travacare, Coram, and Caremark. He is a graduate of the Albany College of Pharmacy and Union University with a Masters degree in Health Systems Management, and he maintains his pharmacist license in New York State.

Jim was a member of the medical team for the Winter Olympics in Lake Placid, New York, and continues to volunteer for various organizations. Jim is a member of the American Society of Clinical Oncology and the Association of Community Cancer Centers. He resides in upstate New York.

After serving patient populations during her career in public health at the Centers for Disease Control and Prevention, Joy McVey Hugick became a patient herself. In August 2010, she had an acute onset of GI symptoms, which was later diagnosed as post-viral gastroenteropathy causing severe dysmotility throughout her gastrointestinal tract. Initially, Joy was on home parenteral nutrition. She transitioned to home enteral nutrition and continues to rely on tube feeding for most of her daily nutrition.

After taking the time she needed to adjust to her new normal, Joy attended her first Oley conference in 2015 where she was inspired to become an Oley Ambassador. As an Ambassador, Joy provides peer-to-peer support to consumers and caregivers, as well as sharing the patient/consumer perspective with clinicians, manufacturers, and policy makers. Joy enjoys blending her public health training with her personal experience living with a feeding tube.

While Oley is a big part of Joy’s life, she is also active in her local alumnae chapter of Kappa Delta Sorority and volunteers weekly at Emory St. Joseph’s Hospital. She also enjoys practicing yoga, reading, cooking, knitting, and spending time with her family. Joy holds a BA in speech communication from the University of South Florida and resides in Atlanta with her husband, Brad, and their lab rescue, Buddy.

Oley Staff Grows

Oley membership is growing, and so are our programs. To help us achieve our goals, we’ve hired two new part-time staff members, Philip Kellerman and Mary Wootten. Philip and Mary joined the staff as program associates in May.

Philip brings to Oley thirty years of philanthropic work with migrant farmworkers and immigrants. From 1997 to 2011 he ran his own nonprofit, Harvest of Hope, which distributed emergency and educational financial aid to migrant farmworkers and families. He currently volunteers for Volunteers in Medicine of Great Barrington, taking immigrant patients to medical appointments in New York and Massachusetts.

Mary has been a member of Oley since 2012, and she has frequently volunteered in the Oley office and at Oley events. She has been an Oley Ambassador for two years, providing peer-to-peer support.

Mary studied psychology at SUNYIT; is a Reiki master teacher, owner of Lotus Flower Reiki in Troy, New York, and a board member of the S.E.T.H. Foundation; and enjoys volunteering with the Girl Scouts. Mary is the mother of three children ages 9, 7, and 5. Her oldest, Natalie, has had a g-tube since she was sixteen months old due to dysmotility and feeding issues.

We are happy to welcome them.

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Happy Campers

Thank you Fresenius Kabi USA for supporting the Oley Tim Weaver Camp Scholarship that enabled these youth to get to camp last summer. Oley is accepting applications for the scholarship year round online at oley.org/campscholarship, andreaguidi.oley@gmail.com or call (518) 262-5079/(800) 776-6539.

Above: “After the surgeon resected 92 percent of Austin’s intestine at a week old, she told us, ‘His condition is not necessarily incompatible with life.’…Thank you for supporting Austin’s opportunity to attend camp this summer and proving [many years later] that Austin’s medical condition is not necessarily incompatible with a crazy-fun camp experience with unforgettable memories that will last a lifetime!”

Left: “Camp lived up to everything Anna could imagine and much more. Being surrounded by kids with similar needs was so normalizing. Nothing I could ever give her at home, or in our community could ever come close to what she was given at camp: The opportunity to grow and explore, to try new things, and to meet new friends who accepted her for who she is.”

Oley Hosts Grand Rounds

The Oley Foundation is excited to host Grand Rounds at Albany Medical Center on October 26, 8:30 to 9:30 a.m. Grand Rounds are formal presentations where medical problems and treatment options are presented to the medical community. They help clinicians keep up-to-date in areas that may be outside their areas of expertise and provide an important opportunity to medical students and residents. Kishore Iyer, MBBS, FRCS, FACS, Director of the Intestinal Failure Rehabilitation and Transplant Program at Mount Sinai, New York, New York, will speak about intestinal failure. Join us to listen to this highly regarded surgeon and to meet other Oley members. Oley will host a gathering for consumers, family members, and clinicians after the talk. Contact Oley to RSVP and get additional details: harrinc@mail.amc.edu, or (518) 262-5079.
on HPN so I'd be strong enough to survive the surgery and the critical year post-transplant.

The surgeon had spoken with the medical team who oversaw my HPN and they had told him they were concerned about episodes of non-compliance on my part. A demonstrated history of patient compliance was critical to being accepted into the transplant program. The surgeon explained it was a matter of life and death, especially during the first year. I realized they also wanted to make sure I was worthy of organs that otherwise would have gone to someone else.

This was a defining moment for me. I knew I felt healthy fewer and fewer days, and eventually I would die from complications related to Crohn's. I looked at everyone in the room and said I would do whatever I needed to do, including going back on HPN.

The following week, after a short but contentious meeting, the surgeon who oversaw my HPN at my local hospital agreed to put me back on HPN five days a week, twelve hours per day. At a visit two weeks later, he seemed satisfied I was being compliant, based on my weight gain and the weekly reports from my visiting nurse.

Several weeks later my parents and I traveled back to the transplant center. The nurses weighed me and made sure they had all the medical records necessary for the doctors and board to review. My weight was up to around 140 lbs. I felt we were heading in the right direction, although I still felt tired and found it hard to get myself out of bed.

During this visit, discussion focused on my teeth. They had been deteriorating, due largely to my disease, dry mouth, and medications I had been on since childhood, and I had already had twelve teeth removed. Now all but four of my adult teeth would have to be pulled prior to transplant surgery. My suppressed immune system and the anti-rejection drugs I would be taking would leave me susceptible to severe infection or death. The thought of having my teeth pulled and wearing dentures was a big deal to me, and the extractions and dentures would be expensive.

Support
With my permission, the transplant team gave my phone number to a woman about my age who had undergone intestinal transplant about a year earlier. She had had digestive health issues from birth. She texted me, and said she was doing exceptionally well.

She and I have continued to communicate, which has been very helpful for me. It gave me insight on what to expect, and it is nice to talk to someone who knows exactly what it is (or was) like living with an acute illness.

Back to the Center
In December, we returned to the transplant center for the fourth time. Our day began at 3:30 a.m. I had butterflies in my stomach and my normally stoic parents were nervous. At this visit we expected to hear whether I had been accepted as a transplant candidate.

In the examining room, the nurse practitioner greeted us with a smile. My dad, filled with anticipation and knowing I'd been gaining weight, asked if I had been accepted. Without total commitment, she said things were looking good and confirmed that they'd received copies of all the required slides, scans, and records.

Moments later the doctor entered. Upbeat, he said he was happy with my weight gain and apparent compliance with the HPN program. He reiterated that I needed to be 110 percent compliant if I wanted to survive the surgery. Then he became serious. He wanted to be sure we understood death was a real possibility, though they were working hard to improve the odds of survival.

He then stated that the criteria for transplant surgery have nothing to do with an individual's quality of life. The criteria are established by the government, i.e. Medicare, and passed down to the medical facilities that perform the transplants. Based on the current guidelines, I would literally have to be having complications of HPN in order to be placed on the organ transplant waiting list.
My mouth dropped and heart sank. I challenged the doctor, stating that following these guidelines, the patient would be too weak to survive the surgery and that as I understood it, by gaining weight and getting stronger I would be a better candidate. He replied that he had no doubt I would be back soon to have a transplant. It was likely that I would experience problems with HPN, as I had the previous year, and if they discontinued the HPN, my weight would plummet and I would become dehydrated and hospitalized—that would be the appropriate point for transplant, but as long as I was seemingly doing well on HPN, there was no “indication for transplant.”

My parents were visibly upset. My mom asked, “What parent would want to set their child up for failure and watch them deteriorate to the point of death?” The room went silent.

The train ride home was long and emotional. There was little to no quality of life for me, just days where there was less suffering and pain. The surgeon’s explanation seemed to defy logic, that poor quality of life, while understandable, in of itself was not sufficient reason to proceed with transplant.

Driven by the love of my family and my love for God, I try to be optimistic, but I can’t say I never get angry. Most of my friends have careers and are ready to settle down. Many have homes and children. I, too, have dreams and wish I could find someone to call my soul mate. However, I would not want to burden another person with the health issues associated with my Crohn’s.

Tough Times in the New Year

2016 started off quietly, but as the saying goes, it was the calm before the storm. On January 14, I met with the surgeon who had performed the kidney surgery. He said things looked good.

The following day, my mom and I went to a community health clinic, where they said they would take out two teeth at a time. That meant it would be seven months before I would be ready for transplant surgery. Another oral surgeon would pull all fourteen teeth at once, but that option was more expensive.

The next week, I met with my GI doctor. I was having trouble swallowing, and he was concerned about a possible blockage in my esophagus. He was also concerned that something was amiss with my liver or gallbladder because my liver counts were high.

My first swallow test came back as inconclusive. They scheduled another. Then I had a consult with a specialist, who noted that stones had possibly developed in my gallbladder and my bile ducts might be blocked. On his recommendation, an endoscopic retrograde cholangiopancreatography (ERCP) was performed in February. They cleaned out the bile ducts and removed six large stones from my gallbladder, which we hoped would help lessen the constant nausea and tiredness I had been feeling.

In early March, however, my parents and I got the flu, which left me severely dehydrated and even weaker. We rescheduled our appointment with the transplant center for March 30. On March 23, I had an appointment with the physician in Rhode Island who, along with his staff, was overseeing my HPN and nutritional needs. He commented that my white blood cell count was slightly elevated.

Still weak, I again rescheduled my appointment with the transplant center. A few days later, I suddenly began to vomit. After a couple of days of vomiting I was admitted to the hospital, where they discovered my gallbladder was inflamed.

They thought they could save the gallbladder by placing a tube into it to allow fluids to drain. In the end, however, that surgery was just the first in a series of surgeries and complications that ended with the removal of my gallbladder. After twenty-eight days in the hospital and serious weight loss, I was finally discharged.

Silver Linings

Not long after, the area around the incision from the removal of my gallbladder looked red and was painful to the touch. My doctor’s office told me to return to the ER, where they did a direct admit. It was a good call, as I had a nasty infection at the site. I was placed on IV antibiotics and remained in the hospital for five days.

They say good things can come from bad events, which I believe. During my hospital stay, I was visited regularly by the members of my nutrition team, who, along with my visiting nurse, have basically kept me alive over the past several years via HPN and IV lipids.

A doctor on this team asked for permission to bring the transplant center team up to date.

Transplant, cont. pg. 8
OFF OF LOVE AND NECESSITY
I originally developed Liquid Hope for my
father when he required an enteral formula.
I simply wanted him to receive all the benefits
of an organic, whole food, plant-based diet.
There was nothing available that came close
to meeting the qualities that are important
to me. Later, we developed Nourish with children
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  (Associated with an anti-inflammatory diet)
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Transplant, from pg. 7

on my latest surgeries and deteriorating health. I agreed. This doctor is
a compassionate caregiver who knows firsthand the physical and mental
pain Crohn’s and colitis can inflict on patients and family members.
She began communicating with the transplant team immediately.
Within two weeks of my discharge, I received a call from the transplant
team. The nurse practitioner informed me unofficially that after almost
a year of traveling back and forth to the center, of spending long hours
on the phone fighting with medical care providers, and experiencing
sleepless nights, I would be accepted as a transplant candidate.

I was light-headed. I hung up and informed my parents, who looked
at each other tearfully and unable to speak.

Confirmation
On June 29, all but four of my teeth were pulled. When my gums
healed, these teeth would help anchor my dentures. My family was
amazed when several hours later I was goofing around. Humor is the
best medicine, especially when you can make others laugh.

On July 6, our train left at 5:40 a.m., heading toward the transplant
center. I was nervous. At the center, they took my weight and blood
pressure and verified my list of medications, which read like a grocery list
(lol). When the surgeon came in, we went over my health history from
the past year. He stated that I was HPN dependent, and with my liver
tests already being abnormal, in the long run it would negatively impact
my liver. We did not want to chance my losing another vital organ, he
continued, and within a week my name would be placed in the national
database for matching organ donors.

The surgeon ordered blood work to ensure I did not have certain
antibodies present that would increase the risk of rejection of the trans-
planted organs; a CT scan of my chest and lower stomach; a meeting
with the staff cardiologist; and another TB shot and a hepatitis vaccine.

We were told to have our phones with us at all times. Once a matching
donor was located, we would have six hours to respond to the hospital
for the surgery. If we were unable to do so, the organs would go to
another recipient. We could conceivably be reached in as soon as eight
weeks. The surgeon stated that the odds for survival of this procedure
were around 75 to 80 percent and that they were improving each year.

The Call
We received the transplant call on Friday, October 21, 2016, at 8:07
p.m. We had been told we could expect a call very soon, but it was
stressful nonetheless when the phone rang and we saw where the call
was originating. My mom and dad huddled around me as I spoke to the
woman from the transplant center. She said they had a matching donor
and asked if I agreed to accept this offer. Without hesitation I said yes.

We had prepared our overnight bags several weeks prior, and only
had to add a few last-minute items. It was thundering and pouring
rain during the entire three-hour drive to the transplant center. My
dad is a retired police officer and used to driving in adverse conditions,
but this trip was different.

My parents and I arrived at the center at midnight and were directed
to the surgical prep floor where we waited until about 9:30 a.m. One
of the surgeons on my transplant team had flown out to inspect and
procure the donor organs in a technically demanding operation, and
accompany them on the trip back to the transplant center, where my
surgeon would have already started on my operation.
My parents accompanied me to the surgical floor as they began preparations. We were all sleep deprived and running on adrenalin. My parents were whisked away to the family waiting area for what seemed like eternity, as my surgery lasted approximately nine hours.

The first twenty-four hours after surgery were difficult. Being under anesthesia for that length of time plays havoc with your memory and thought processes. It’s hard to explain, though while on the intensive care unit I witnessed other transplant patients who had a similar experience. However, on the third day I was up and walking, at the amazement of my surgeons and nursing staff. On day five I was allowed to slowly begin soft food intake, which earned me the nickname of “Rock Star” as my progress exceeded the expectations of my medical team and support staff.

For the first several days, my parents stayed at a family living center that the transplant center subsidizes, several blocks from the hospital. They went home, then returned several days later and remained through the weekend. They repeated this pattern over the next month.

I progressed very rapidly over the next several weeks, partly due to my positive attitude and the skill of my surgeons and care team. The care I received was exceptional and everyone at the center was caring and considerate. To everyone’s amazement, I was discharged from the main hospital in thirty days. Normally, patients receiving a small bowel/large intestine transplant spend forty-five to sixty days hospitalized.

I stayed at the family living center for eight days, due to frequency of doctor visits, etc., and in case of an unexpected emergency. My dad stayed with me, and we passed the time walking (yes, walking) three blocks to the hospital each day, or in a park people watching and feeding the pigeons.

My official discharge was November 22. I had asked if I could spend Thanksgiving with my family back home, and given my progress and tugging on a few heart strings, my wish was granted. The ride home seemed much shorter than that ride we had taken October 21.

My PICC line was pulled on the day of my discharge. I am no longer required to take HPN (yeah!). I do take daily doses of anti-rejection drugs. These affect my kidneys, which were already weakened after twenty-three years of living with Crohn’s disease. This, however, is but another hurdle I am determined to overcome.

In the six months since my transplant surgery, life has changed for me and my entire family. Not a day goes by that we don’t think of the young man whose life tragically ended, and of his family who at a time of tremendous suffering and loss had the compassion and strength to donate his organs, which saved the lives of many, including me. There is little question in my mind that the healthy condition of the small bowel and partial large intestine I received resulted in my recovery and a discharge of only thirty days.

There have been many coincidences regarding the health care professionals in my life. I feel a divine power has brought these special people together not only to save my life, but to make a difference in the lives of the countless others who live with Crohn’s and colitis.
Medicare Coverage, from pg. 1

have, but especially with Medicare. It is often a surprise at the time of discharge that a patient does not have coverage for HPN and other related infusion therapies under Medicare. This is because Medicare policy is not always understood or interpreted correctly, and/or the objective tests and studies required have not been done or are not available in the medical record.

Why is this important to you if you are already on HPN and/or home enteral nutrition (HEN, or tube feeding)? We want you to be aware of existing Medicare laws that may affect you now, or could affect you if you transition to straight Medicare in the future. We also want you to understand the Medicare qualification process for coverage (why you might need to undergo a tube feeding trial, for example), so you can work with your health care and infusion providers as a partner in this process.

Medicare HPN Policy: Background

Medicare is the federal health care program enacted by Congress as part of the Social Security Act of 1965. It is the largest health insurance program in the United States. Medicare HPN policy has remained the same for almost thirty years!

Medicare coverage is divided into Parts A, B, C, and D and each part provides different benefits. For almost thirty years, parenteral (PN) and enteral nutrition (EN) therapies have fallen under the Prosthetic Device Benefit of Part B. The Center for Medicare and Medicaid Services’ (CMS) rationale is that a device used to administer PN or EN serves as a prosthesis by replacing an organ or function of an organ that is permanently impaired.

If specific criteria related to any one of seven GI conditions have “permanently” (defined as three months or longer) prevented absorption of nutrients needed to maintain weight and strength commensurate with the patient’s health status, AND it is documented objectively in the manner required, then Medicare may cover HPN accessories and/or supplies under Part B. Professional services, clinical assessment, monitoring, and actual ongoing management of the patient by the HPN provider** (see note on page 14) have never been covered by Medicare.

The Medicare concept of “permanent” impairment of the small intestine is often challenging for clinicians and consumers* who approach HPN with the hope that over time a consumer’s dependence on PN may be reduced through bowel adaptation, as well as diet and medication management. Medicare policy says, “Permanence does not require a determination that there is no possibility that the beneficiary’s* condition may improve sometime in the future. If the judgment of the attending physician, substantiated in the medical record, is that the condition is of long and indefinite duration (ordinarily at least 3 months), the test of permanence is considered met.”

Table 1 provides a checklist of the clinical situations (A–H) where Medicare will cover HPN. In addition to meeting the test of “permanence,” there must be clear objective evidence that the GI tract, specifically the small intestine, is non-functioning. A completed Durable Medical Equipment Medicare Administrative Contractor (DME MAC) Information Form, formerly referred to as a Certificate of Medical Necessity, a Detailed Written Order, and extensive objective

Medicare Coverage, Table on right, Text cont. pg. 12
## Table 1. Medicare Checklist for Determination of Coverage for Home Parenteral Nutrition

### Section 1.
All patients must meet 1 and either 2a or 2b in Section 1.

1. The patient will require PN for a minimum of 90 days. Documentation by the attending physician must be in the medical record prior to discharge. PN will be denied as non-covered in situations involving temporary impairments.
2. The patient must have:
   a) Condition involving the small intestine and/or its exocrine glands which significantly impairs the absorption of nutrients OR
   b) Disease of the stomach and/or intestine which is a motility disorder and impairs the ability of nutrients to be transported through the GI system.
   There must be objective evidence to support the clinical diagnosis.

### Section 2.
In addition to Section 1, patients must meet any one of A–F in Section 2, OR all of Section 3.

A. The patient has undergone recent (within the past 3 months) massive small bowel resection leaving less than or equal to 5 feet of small bowel beyond the ligament of Treitz.
B. The patient has a short bowel syndrome that is severe enough that the patient has net gastrointestinal fluid and electrolyte malabsorption evidenced by:
   1. Electrolyte malabsorption and abnormalities AND
   2. GI fluid intake of 2.5–3 L/day resulting in enteral losses that exceed 50% of the oral/enteral intake AND
   3. Urine output of < 1 L/day
C. Patient requires bowel rest for at least 3 months and is receiving intravenously 20–35 cal/kg/day for:
   1. Symptomatic pancreatitis with or without pancreatic pseudocyst OR
   2. Severe exacerbation of regional enteritis OR
   3. Proximal enterocutaneous fistula where tube feeding distal to the fistula is not possible
D. Patient has COMPLETE mechanical small bowel obstruction where surgery is not an option.
E. Patient is malnourished and has severe fat malabsorption as evidenced by:
   1. 10% weight loss < 3 months AND
   2. Serum albumin 3.4 gm/dl AND
   3. Severe fat malabsorption where fecal fat exceeds 50% of oral/enteral intake on a diet of at least 50 gms of fat/day as measured by a standard 72-hour fecal fat test
F. Patient is significantly malnourished and has a severe motility disturbance as evidenced by:
   1. 10% documented weight loss over < 3 months AND
   2. Serum albumin 3.4 gm/dl AND
   3. Severe motility disturbance of the small intestine and/or stomach that is unresponsive to prokinetic medications and is demonstrated scintigraphically or radiographically. These studies must be performed when the patient is not acutely ill and is not on any medication which would decrease bowel motility (see reference below, *Parenteral Nutrition LCD L33798*, for more specific detail for Situation F).

### Section 3.
Patients who do not meet criteria A–F but have a moderate abnormality of A–F in Section 2 must meet criteria 1 and 2, PLUS G and H.

1. Modification of the nutrient composition of the enteral diet (i.e., lactose free, gluten free, low in long chain triglycerides, substitution with medium chain triglycerides, provision of protein as peptides or amino acids, etc.) AND
2. Utilizing pharmacologic means to treat the etiology of the malabsorption (e.g., pancreatic enzymes or bile salts, broad spectrum antibiotics for bacterial overgrowth, prokinetic medication for reduced motility, etc.) AND
G. The patient is malnourished (10% documented weight loss over 3 months or less and serum albumin less than or equal to 3.4 gm/dl) AND
H. A disease and clinical condition has been documented as being present and it has not responded to altering the manner of delivery of appropriate nutrients (e.g., slow infusion of nutrients through a tube with the tip located in the stomach or jejunum).

*Adapted from: Parenteral Nutrition LCD L33798, Policy Article A52515; CMS Pub. 100-03 (National Coverage Determinations Manual), Chapter 1, Section 180.2, October 2015.*
documentation from the medical record to support the criteria is the minimum required by CMS. Table 2, the original version published by the former DMERC (now called DME MAC) Region D over a decade ago, outlines the necessary documentation required for each situation.

Medicare requires an attempt at tube feeding when there is a “moderate abnormality” of a condition in situations A–F (see Table 1), i.e., in cases where the documentation does not exactly meet criteria for coverage, so additional information, such as documented weight loss, a low albumin, attempts at medication and diet modifications, and a tube feeding trial is required. Currently, the policy makes no exception for situations where a tube feeding trial may not be clinically appropriate or possible. (Additional tables available online or upon request to Oley outline examples of “moderate abnormalities” and Medicare’s definition of a tube-feeding trial.)

The Claims Process

The initial claims submission process is different today than in years past, which causes confusion among some providers and could potentially place families at significant financial risk. In the past, coverage was approved or denied by CMS from the start. Today, initial analysis of whether Medicare will cover the PN falls completely on the infusion provider, who then informs the physician if the consumer is “approved” for HPN coverage at time of discharge. If that provider does not fully understand the policy or interpret it correctly, it could have significant financial impact on the consumer later on when the provider realizes the consumer actually has no coverage and is then responsible for payment.

Supporting medical records should be obtained by the infusion/HPN provider prior to the start of care so the provider can submit required records when a claim is audited. CMS can audit a claim up to three years after a claim has been paid, which could potentially end up being as many as five years after an incident of care or an HPN shipment was provided. If documents cannot be produced in an audit, the government recoups all payments and the beneficiary could be at risk for the total amount, which could be tens of thousands of dollars.

If a claim is denied after an audit has been conducted, there are five levels of appeal within CMS that infusion providers and beneficiaries can pursue. According to statistics from the Office of Medicare Hearing and Appeals, the average time frame to reach a Level 3 Administrative Law Judge adjudication in 2014 was 547 days, indicating a significant backlog. Since audits are very common, infusion providers should carefully adhere to Medicare PN policy by collecting necessary qualifying documents prior to discharge, which should help to protect the consumer financially in the long run. The consumer should keep copies of their medical records as well, in case they can help provide missing documentation in the future.

Challenges with Medicare and Home Infusion Therapies

Medicare is the only payer in the United States that fails to recognize the clinical and cost benefits of providing infusion in the home setting. Currently, most infusion therapies related to HPN are not covered by Medicare, even when medically necessary (see table 3).

The Oley Foundation, the American Society for Parenteral and Enteral Nutrition (ASPN), and the National Home Infusion Association (NHIA) have lobbied CMS for years in an attempt to change existing law so that meaningful coverage for home infusion therapy for Medicare beneficiaries is available. In addition, current policy for HPN severely limits access to the therapy, with few patients meeting the government’s criteria, either due to the test of permanence required, or non-qualifying conditions for PN such as malnutrition, GI/nutritional complications due to cancer treatments or bariatric surgery.

An abstract published in 2007 reported that only 16 percent of Medicare PN referrals (over a large geographically and medically diverse sample) received by a national infusion provider met Medicare HPN policy requirements (Allen P. Medicare TPN coverage criteria. Nutr Clin Pract. 2007;22[1]:106). Ten years later, another national infusion provider with similar referral statistics demonstrated that even fewer Medicare beneficiaries referred for HPN (10.5 percent) met the restrictive policy requirements (Allen P. Medicare parenteral nutrition policy 20 years later. Clinical Nutrition Week 2016, ASPEN, Abstract S21:25).

Patients who do not qualify for coverage and do not have a secondary major medical insurance policy are left with few desirable options, however Medicare beneficiaries do have coverage for PN in a skilled nursing facility (with Part A restrictions). If HPN does not meet coverage criteria because length of need was not permanent, the patient may have coverage in the skilled nursing facility setting (see table 4).

Transitioning to Medicare

A significant challenge for HPN consumers and infusion providers is when the consumer transitions from a commercial payer to Medicare when they meet disability criteria or turn 65 years old. There is no such thing as “grandfathering” of HPN coverage when a consumer flips to Medicare from another insurance company. Further, there are no clear guidelines from CMS on how to “qualify” consumers who are already on HPN who enroll into the Medicare program.

Sometimes physicians and providers must examine medical records and documented clinical situations from when the patient first started on PN, if these even exist, and attempt to qualify the patient retroactively. Most insurance providers require only a statement of “medical necessity” for HPN coverage. This means the Medicare criteria, including testing, objective studies, and length-of-need documentation, may never have been completed when HPN was started months or years before. It may be advantageous for consumers just starting on HPN to maintain a file of records in the event they may need them if/when they switch to Medicare.

Asking the physician to document an estimated length of need for PN therapy in the chart may also prove invaluable in the future. Most commercial payers do not follow a “permanent impairment” deal breaker for HPN coverage, so the documentation required by Medicare when PN was initiated, i.e., a statement of how long the attending physician thought the patient would need HPN, may not exist. Despite the fact that there is almost always medical necessity for HPN consumers switching to Medicare, there will be no coverage for HPN if: (1) there is no “qualifying” situation (A–H on table 1); (2) the objective evidence is not available to support the qualifying situation; or (3) there is no documented length of need of 90 days or longer, even in cases where a patient has been on HPN for many years.
Table 2. Documentation Required by Medicare (Adapted from DMERC Region D 20069)

**Situation A**
Massive Small Bowel Resection
Medical Records Should Document
- Date of surgery
- Details of surgery
- How much small bowel is remaining beyond the ligament of Treitz
- Estimated length of need for HPN
Suggested Records*: 1, 2, 3, 4

**Situation B**
Short Bowel Syndrome
Medical Records Should Document
- Cause of short bowel syndrome
- 24-hour I & O documenting oral/enteral intake, stool output and urine output
- Electrolyte abnormalities upon admission
- Estimated length of need for HPN
Suggested Records*: 1, 2, 3, 4, 5, 6a, 6i

**Situation C**
Bowel Rest (pancreatitis, enterocutaneous fistula [ECF] or severe regional enteritis/Crohn’s disease)
Medical Records Should Document
- One of the above diagnoses that requires bowel rest
- If ECF, statement that tube feeding distal to the fistula is not possible
- How long the attending MD anticipates patient will need bowel rest
Suggested Records*: 1, 2, 3, 6

**Situation D**
Complete Mechanical Small Bowel Obstruction
Medical Records Should Document
- Presence of complete small bowel obstruction (radiographic reports)
- Surgical options if any
- Estimated length of need for HPN
Suggested Records*: 1, 2, 3, 4, 6

**Situation E**
Severe Malabsorption
Medical Records Should Document
- Cause of malabsorption
- 3-month weight history**
- Serum albumin less than normal
- 72-hour fecal fat test results documenting fat malabsorption of ≥ 50% of fat intake via calorie counts documenting high fat diet
Suggested Records*: 1, 2, 3, 6b, 6c, 6d, 6g, 6i

**Situation F**
Severe Motility Disturbance
Medical Records Should Document
- Etiology of motility disturbance
- 3-month weight history**
- Serum albumin less than normal
- Prokinetic medication history
- Nuclear isotope or x-ray motility study
Suggested Records*: 1, 2, 3, 6b, 6d, 6e, 6f, 6g

**Situation G & H**
Other Qualifying Condition and Failed Tube Trial
Medical Records Should Document
- 3-month weight history**
- Serum albumin less than normal
- The diagnosed “moderate abnormality” per Medicare policy
- Enteral tube feeding trial(s)
Suggested Records*: 1, 2, 3, 4, 6d, 6f, 6g, 6h

**Key**
*Suggested Records:
1. Admission history and physical examination (H & P) notes
2. Progress notes
3. Discharge summary
4. Operative reports
5. 24-hour intake & output (I & O) records
6. Diagnostic test results
   a. Serum electrolytes
   b. Serum albumin
   c. 72-hour fecal fat results
   d. Nutrition assessment
   e. Small bowel motility (the criteria does not specify)
   f. Medication records
   g. Weight history
   h. Details of enteral trial (see table “Medicare’s Definition of an EN Tube Trial for Situations G and F,” online)
   i. Other pertinent tests

**Weight on admission compared to documented weight 3 months ago**

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Table 3. HPN-related Infusion Services NOT Covered by Medicare

- Intravenous hydration
- Catheter care
- Anti-infective therapies
- Ethanol locks
- Nursing
  - Covered under Medicare Part A, but ONLY if patient is homebound
Health care practitioners caring for HPN patients who will be turning 65 should guide those patients to examine all insurance options available regarding original Medicare, Medicare Advantage, or replacement plans before dropping existing insurance coverage.  

Selecting a Provider  
Selection of HPN/infusion providers who are fluent and compliant with Medicare law may protect beneficiaries from financial hardship down the road. Some providers will accept Medicare PN referrals quickly and without a thorough assessment, then later discontinue care when they learn there is no reimbursement from CMS. If an infusion provider quickly accepts a Medicare PN case without a complete review of the documentation prior to discharge, it should be a red flag to everyone involved, including the beneficiary. Qualified, reputable HPN providers offer consultative guidance in the way of a “records review” at the time of referral to help physicians navigate the complexity of the policy with the ultimate goal of protecting the beneficiary.

Table 4. Possible Options When a Patient Has No Coverage for HPN under Medicare

- Secondary major medical insurance policy may have HPN benefits  
- Skilled nursing facility for completion of therapy if short term (i.e. less than 90 days)  
- Hospital pays the infusion provider a per diem/daily rate for HPN  
- Part D plan may have partial coverage for premixed PN products/individual PN ingredients; there will be a copay for pump/tubing/supplies/services [Editor’s note: The Oley Equipment-Supply Exchange may be a resource for some supplies]  
- PN is discontinued prior to discharge if appropriate

During open enrollment, consumers should investigate alternative insurance options and/or Medicare Advantage or replacement plans that offer more meaningful benefits if they will need home infusion now or in the future. Infusion providers should be able to provide guidance.  

Conclusions

Until new laws are passed and coverage for HPN becomes more accessible under Medicare, referrals for HPN should be made as early as possible to allow for thorough examination and review of medical documentation and allow for the possibility that additional testing may be required by Medicare. This may help ensure that the beneficiary will have coverage for HPN and would not be at risk for denial of payment when an audit is conducted. As a consumer, it is important to understand the paperwork process when therapy is initiated. If your provider has assured you there is coverage under Medicare, there should be no need to sign an Advanced Beneficiary Notice (ABN) at the start of care. The ABN basically says the service may not be covered and you could potentially have financial liability. The ABN also allows the provider to bill a secondary insurance plan (if you have one), if Medicare denies coverage. If you are asked to sign, be sure you understand why.

Consumers and providers of HPN should develop a stronger understanding of the Medicare reimbursement system in order to advocate for access to care. Physicians should document the clinical necessity of HPN, backed up by objective evidence and testing, along with an estimated length of need for therapy for all patients going home on PN—as if they needed to meet Medicare criteria. Consumers who currently have private insurance may eventually transition to Medicare and this supporting documentation will be required for a successful transition and continuation of HPN therapy. Consumers switching to Medicare should not drop current insurance plans until they are familiar with Medicare options available should they require home infusion in the future. More information can be found at www.medicare.gov.

*In this article, patient, consumer, and Medicare beneficiary all refer to the person needing home parenteral nutrition (HPN).  
**Provider refers to the home care company, or infusion company, that provides the HPN.

HPN Awareness, from pg. 1

Reach out to your local newspapers and TV and radio stations, if you are comfortable sharing your story. Share a noteworthy event in your life (an HPN anniversary, a graduation or wedding, etc.) around which they can build a story. There may be someone in your community who will be encouraged by reading an article about your experiences.

Wear your free HPN Awareness Week pin, share them with friends, family, your clinicians...and help raise awareness!  

Submit photos or videos to Lisa Metzger at metzgel@mail.amc.edu or The Oley Foundation, 43 New Scotland Ave. MC-28, Albany Medical Center, Albany, NY 12208, by July 27 (or sooner). For free pins, go to www.oley.org, e-mail Lisa, or call Oley at (518) 262-5079. Give us a call if you’d like help with a press release.

Thanks to Baxter Health care for underwriting the pins and promotional materials for HPN Awareness Week 2017.
Notable Individual Gifts
Among the individual contributions received, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. We are grateful for the following gifts received from March 4 through May 19, 2017:

In Honor of: All those I pray for and love who depend on feeding tubes; Hadar and Melanie Birger-Bray; Philip DiVito; the hopeful recovery of Natalie Ginsburg; Joanne Platt; the awesome ThriveRx employees and team walking in the Oley Walk-A-Thon; my amazing sister, Emma Tillman

In Memory of: Dr. John Balint; Joseph Longobardi; Jody McCard’s brother, Steve; Dawn Smith; Don Young

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Thank you for all gifts and the kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration.

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 (518) 262-5079.

Felice Austin
Jane Balint, MD
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Patty & Darrell Woods
Rosaline Ann & William Wu

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

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Albany Medical Center
Albany, NY 12208

Can’t Make the Conference?

Many sessions will be streamed live and recorded for future viewing. Go to www.oley.org to watch.

Oley June–October 2017 Calendar

June 20: Oley Webinar, Treatment Options for Gastroparesis
June 28–July 1 (clinicians only): Oley attending and exhibiting at Congress of the Intestinal Rehabilitation and Transplant Association, New York, NY
July 5–9: Oley Annual Consumer/Clinician Conference, Old Greenwich, CT
August 7–11: HPN Awareness Week
August 22–26: Oley exhibiting at United Ostomy Associations of America conference, Irvine, CA
September 16: Oley Regional Conference (in conjunction with AVA meeting), Phoenix, AZ
September 16–19: Oley attending, exhibiting, and presenting at Association for Vascular Access (AVA) conference, Phoenix, AZ
October 26: Oley hosting Grand Rounds, Albany Medical Center, Albany, NY, see page 5
Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

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

Miss a Webinar? Watch It Online
Oley’s new webinar series has covered great topics, including treatments for short bowel syndrome, clogged feeding tubes, travel, and coping. Each webinar is recorded, so if you can’t make the live presentation, you can watch it later at your convenience. Slides and handouts from the webinars are available online as well. Go to oley.org/webinars for details.

Join Oley in Phoenix
September 16, 2017, Oley will be holding a one-day regional meeting in Phoenix, Arizona. Don’t miss this opportunity to learn from experts, and network with fellow consumers and caregivers. Go to oley.org/oleyregionals for details.