Writing Winning Insurance Appeal Letters

Susan Mina Agrawal

This is a slightly revised version of an article that appeared recently in the e-magazine Complex Child. It is printed here with permission. Complex Child can be found at www.ComplexChild.com (see page 6). Note that while this article was initially written for parents, the strategies outlined can be applied in a wide range of circumstances.

Like many parents of children with complex medical issues, we receive many insurance denials. We probably average three a week. Many of these are simple to resolve, but I have come up with a variety of strategies to respond to even the most difficult insurance denials.

What I typically do is write a letter from me (the parent) describing in detail why the appeal should be granted. Surprisingly, much of the time just this one letter will win the appeal. If it does not or the insurance company requests a physician’s letter, I ask the physician to mail or fax me the letter and add my own letter to it, supplementing the physician’s statement.

Here are some of the strategies I use when appealing a denial, followed by a sample letter with instructions on page 7. Good luck!

Show Them the Money

Insurance companies care about profit. The best way to win an insurance appeal is to prove to the insurance company that paying the claim in question will save them money. Every appeal letter I write, unless it’s in response to an error in coding or processing, includes a statement on how the item or procedure in the claim

Medicare Update:
EN Competitive Bidding

Who, What, When

Starting July 1, 2008, some enteral consumers who receive Medicare will be affected by the Competitive Bidding Program, mandated by Congress through the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. Under the program, a competition among suppliers who operate in a particular bidding area will be conducted and contracts will be awarded to the suppliers who offer the best price and meet applicable quality and financial standards.

The program applies to people with Original Medicare (not those with a Medicare Advantage Plan) whose permanent residence is in a ZIP code that is part of one of the competitive bidding areas or who are traveling to or visiting one of these areas.

Where

The program will initially take effect in the following ten pilot areas:

- California — Riverside, San Bernardino, Ontario
- ...
they are denying will save them money in the long run. I most commonly cite how approving this claim will prevent future hospitalizations.

Our insurance company, for example, refused to pay for GJ-button extension sets because my daughter is not tube fed. She uses the extension sets for gastric drainage and for medications through the J-tube, and receives all of her nutrition parenterally. I argued to the insurance company that they could pay for the extension sets at a cost of about $200 per month, or they could pay for her fourteen J-tube medications to all be given IV, at a cost of approximately $1000 per day. The appeal was approved immediately.

Check for Errors

Many times claims are denied because of simple mistakes, such as improper coding or wrong identification numbers. Some of these can be handled with the insurance company, while others must be taken up with the provider. These appeals are usually pretty easy to win, but often require a request to speak to a supervisor.

If your child has secondary Medicaid, many claims will be denied because the doctor or hospital submitting the claim has indicated that you have secondary insurance. The insurance company denies the claims because you have not reported to them that you have secondary insurance. In reality, since most private insurance companies do not work with Medicaid, they keep no record of Medicaid in your file, no matter how often you report that you have it. Sometimes all you need to do is call them monthly to remind them that your child’s secondary insurance is Medicaid and they need to process your claims.

Don’t Give Up

I have fought many appeals for as long as twelve months. The insurance companies seem to use the “hassle factor” to try to get you to give up. They will deny and deny again for pointless reasons, all the while hoping that you will give up the fight. Don’t give up!

Medical equipment, like wheelchairs and beds, often is not approved until you jump through many, many hoops. The insurance company often sends out soft denials, or requests for further information, in order to slow down the approval process and get you to give up. Jump through the hoops and you will almost always win! My daughter, who does not walk, sit, or even hold her head up, had her tilt-in-space wheelchair soft-denied three times. The first time the insurance company wanted a physician’s functional assessment (the initial assessment had been done by an equipment specialist); the second time they wanted a statement as to whether she could self-propel a chair or not (a question that should have had an obvious answer based on her two functional assessments); and the third time they wanted a photograph of the chair. We won after submitting all of the requested information.

Co-author Your Letters of Medical Necessity

Let’s face it. Oftentimes your child’s doctor does not know the day-to-day needs like you do. Not does he or she have a lot of time to dedicate to writing letters to insurance companies. If you want a good letter, write it yourself and then e-mail it to the doctor. He or she can edit it as needed, cut and paste it onto letterhead, and be done with it in minutes instead of days. This means a quicker turn-around time for letters and possibly a more accurate letter. I also have the doctor mail or fax me the letter so I can submit it myself with whatever further documentation I have to support the appeal.

Attach Medical Records

Include any and all medical records that would support your appeal, referencing them in your letter. Any medical documentation that supports the claims you have made in your letter will really help your appeal get through medical review unscathed. Also attach a copy of the insurance denial for them to reference. If you are appealing a denial for a product, include a brochure about the product.

Cross Your ‘t’s, Dot Your ‘i’s

Don’t neglect spelling and grammar. Use as many medical terms as you can (appropriately of course) and try to write in as scholarly a style as you can. Whether you fax or mail your letter, make sure all pages contain your child’s name, the insurance identification number, and the claim number. If you fax your letter, make sure you include a cover page listing how many pages are to follow and what they are.

Forget the Sob Story

Insurance companies couldn’t care less if your family is struggling financially, if you have spent many hours fighting this appeal already, or if this procedure will give you another month of wanting to see the doctor. If you have a letter stating you need further documentation, send the minimum necessary. If you don’t have it, don’t argue. If your child uses the equipment, just say so. If you need a letter stating the need for a wheelchair, just say so. If you need a letter stating the need for a bed, just say so. No one is going to deny the need for a bed or a wheelchair. If your child needs a wheelchair, she needs a wheelchair. You and your child will not win the appeal if you are thinking of the insurance company’s thoughts. The insurance companies are not thinking of your child’s needs. The insurance companies are only thinking of their money. You and your child have the rights to the care your child needs. If you are not getting it, find someone who is willing to fight for you.
**Tube Talk**

Thank you to everyone who sent material for the “Tube Talk” column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail Metzgel@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

**Syringe Alternative**

As a polio survivor, one of my priorities must be to prevent overuse damage. Thus I’m constantly looking for ways to prevent putting undue stress on my body. These tips might help tube users with arthritis and other degenerative conditions.

After a few months of bolus feedings with a 60 cc syringe and plunger, I realized that continuing to hold my syringe, use the plunger, and open the tab top cans would ruin my hands — my ticket to independence. The repetitive motion and pressure of the feedings were doing me in. I tried Kangaroo bags on a pole, but that didn’t work. So I asked for a home health occupational therapist (OT) who had experience with feeding-tube users. She and I began looking for simple alternatives to do feedings, such as a makeshift syringe holder that I could comfortably connect from a sitting position.

I discovered a hair dryer holder (see photo) in the Wright Stuff catalogue (www.wrightstuff.biz or 877-750-0376) and the OT custom-molded a piece from splinting material that would fit it and hold the syringe. I have used the adapted feeding-tube holder for over a year. The base slips under my legs and anchors firmly in place.

I also found a “3-in-1” can opener that takes all the stress off my wrist and fingers (www.sammonspreston.com/Supply/product-list.asp?subsection=1623). My OT identified appropriate wrist and hand splints and customized them for me. All these small changes have enabled me to keep doing my own feedings with no stress on my body.

— Marie Latta
latta@mindspring.com

**Food Choices**

Since I’m one of those rare enteral feeders who makes his own blends, I have complete control of my diet. I usually prepare two gallons of blend out of chicken, potatoes, mixed vegetables, a can of tuna, maybe some peanut butter, and often a dose of raisins. After boiling the concoction, I let it cool, then blend it and put it in quart jars. I use the blend for noon and late afternoon. For breakfast, I make a blend of oat cereal.

Once or twice a week my wife Ann and I eat at a fashionable restaurant. For variety, it’s good to go out to eat. After Ann orders a meal to eat in, I order a full meal for later blending. When I tell the waitperson I want to carry my meal home, I usually receive a blank look. Rarely, the waitperson will inquire about my reason, so I tell my story in about twenty-five words or less.

When I later set up my blending operation at home, I often split the carryout food into two or three portions. I find my digestive system is more receptive to strange food if I mix oat cereal with the restaurant food. I guess you could call the oats my buffer food.

I have to avoid broccoli and breads with large seeds. The broccoli is a diuretic and the seeds won’t blend and pass through my tube. Otherwise, any nutritious food is acceptable. The stronger flavors like chili give me a mild taste sensation in my mouth for a while after ingesting them.

— Robert Flute Snyder, DMA
fluteduo@aol.com

Photos by Andrew Conaway
New Jersey Support Group
Is a Family Affair

LeeAnne Bye, with the help and support of her family (husband Allen and children Lauren, Amanda, Matthew, and Samantha) has launched a new local Oley support group in southern New Jersey. LeeAnne has wanted to start a local support group for some time. This spring, it finally happened.

The group had its first meeting in March and has been meeting the second Wednesday of every month from 7:00 to 9:30 p.m. A local church has offered the group its parish hall for the meetings. Thus far, group attendees have been parents of children who are on enteral nutrition for a variety of reasons. The children have enjoyed getting together almost as much as the parents have appreciated sharing and discussing the many issues of parenting children with GI issues!

LeeAnne says, “I’m hopeful that as time goes on and the word gets out the group will continue to grow and be able to share the wonderful support and information we have gotten over the years from Oley.”

This group is open to all consumers and families. If you live in southern New Jersey and are interested in attending, call LeeAnne at (609) 641-9087 or e-mail allenleeannebye@aol.com for more information. Other Oley Regional Coordinators who have information about support groups include Kathleen McInnes in Chicago, IL and June Bodden in Clearwater, FL. Kathleen can be reached at (773) 763-8791 and June’s phone number is (727) 784-9659.

Make Every Internet Search Count for Oley

Make your next Internet search a Good Search. GoodSearch.com is a search engine that donates half its revenue, about a penny per search, to the charities its users designate. You use it just as you would any search engine. It’s powered by Yahoo!, so you get good results. Just go to www.goodsearch.com and enter Oley as the charity you want to support. Just five hundred of us searching four times a day will raise about $7300 in a year without anyone spending a dime!
Do You Have an Undiagnosed Disease?

The National Institutes of Health (NIH) has launched a trans-NIH initiative called the Undiagnosed Diseases Program. This new clinical research program will focus on the most puzzling medical cases referred to the NIH Clinical Center in Bethesda, MD, by physicians across the nation. Program staff expect to see their first patient in July 2008.

To evaluate each patient enrolled in the new program, NIH will enlist the expertise of more than 25 of its senior attending physicians, whose specialties include endocrinology, immunology, oncology, dermatology, dentistry, cardiology, and genetics. William A. Gahl, MD, PhD, clinical director at the National Human Genome Research Institute and an expert on rare genetic diseases, will serve as director of the new program.

“This new program will capitalize on a rich set of skills already at the Clinical Center to help patients with unusual medical conditions. These patients partner with us in clinical research to identify new diseases or new treatment,” Dr. Gahl said.

To be considered for the program, a patient must be referred by a physician and provide all medical records and diagnostic test results requested by NIH. Patients who meet the program’s criteria — as many as 100 each year — will then be asked to undergo additional evaluation during a visit to the NIH Clinical Center that may take up to a week.

For more information about the Undiagnosed Diseases Program, go to: http://rarediseases.info.nih.gov/Undiagnosed. Physicians and patients with specific inquiries may call the NIH Clinical Center clinical information research line at 866-444-8806.
Practical Tips

with your dying child. Including these sorts of statements in your letter may get the letter thrown into the garbage pile. Insurance companies want facts.

Use a Case Manager

Some insurance companies have case managers who handle children with multiple medical issues. See if you can get one. Sometimes they can be extremely helpful in getting appeals processed, though other times they can be utterly useless. If you are one of the lucky ones with a case manager who is actually willing and able to help you, use him or her. Sending the case manager a photo of your child often helps to get the case manager to work harder on behalf of your child. But don’t forget that the case manager ultimately works for the insurance company and his or her goal is still to save them money. You can appeal even if the case manager says it is not worthwhile, or that you will never win.

Check the Laws in Your State

Sometimes states pass laws that require insurance companies to cover certain things, like medical formulas for certain diagnoses or ongoing therapies for children who are not expected to “rehabilitate.” Check your state’s regulations to see if this applies to you.

Appeal to Your Human Resources Department

Your employer’s human resources department is responsible for negotiating the contract with the insurance company. Since they can just as easily take the contract to another insurer the next year, these people actually have some power over the insurers. If the insurance company continues to deny your claim, bring it to the attention of human resources and have them help make calls on your behalf.

Know When to Appeal to Outside Regulators

In general, threatening is not a good idea. But if the insurance denials are causing your child to be denied appropriate medical care, by all means threaten to sue or appeal to whatever state or local boards regulate insurance in your area.

Finally, a sample letter for appealing a denial is on the next page.

Appeal, from pg. 2

Resource for Parents

Complex Child E-Magazine is a new parent-written magazine edited by Oley member Susan Agrawal. The magazine is designed, Susan says, “to provide you [the reader] with the help you need while also letting you share what you have learned.” Complex Child is written by parents of children with complex health issues, who share their personal experiences in easy-to-understand language. Articles address medical issues—from the very basic to the extremely novel and complex—as well as topics related to caregiving, insurance, education, and advocacy.

While not solely devoted to GI and HPEN concerns, Complex Child includes a wealth of information that could be helpful to Oley members. The June edition features an introduction to commonly used formulas as well as an article outlining strategies to prevent or reduce liver disease in children receiving parenteral nutrition. Past articles have addressed vomiting, motility issues, visceral hyperalgesia, fundoplication, cyclic vomiting syndrome, mitochondrial diseases, and eosinophilic disorders.

A Sample Insurance Letter

Your name
Your address
Your phone number

Your child’s name
Your insurance ID number
Your group number
Your claim number for this specific claim
Today’s date

Nasty Insurance Company
10 Denial Drive
Profit, IL 60000

To Whom It May Concern:

Start with a brief introduction, including your child’s name, age, and primary diagnosis. Follow this with a brief description of the claim. Finally, briefly state why the insurance company is wrong in denying the claim:

I am writing this letter on behalf of my daughter, Always Denied, who is two years old and is diagnosed with cerebral palsy. This letter is in regards to claim 10000, denying XYZ Valves as not medically necessary. These devices are essential in preserving her health and significantly reduce her need to be hospitalized. Moreover, they significantly lower her health care costs by providing a way to feed her through her gut.

Give a brief description of your child’s medical conditions and relevant equipment. List as many diagnoses as you can and use as many medical terms as possible (such as gastrostomy instead of G-tube):

Always Denied has a wide variety of medical problems, including cerebral palsy, seizures, hydrocephaly, gastroparesis, reflux, hearing impairment, and sensory processing disorder. She has a gastrostomy for feeding, a VP shunt, and requires an elemental formula. She vomits multiple times per day.

Explain why you need the item or procedure, making sure to show it clearly benefits the child:

Because Always Denied’s stomach does not empty well due to gastroparesis, she vomits her formula as many as ten times per day, and is very bloated and in pain. The XYZ Valves allow her formula to slowly drip into her stomach as it empties, while simultaneously venting out the air. They reduce her pain and vomiting dramatically, often stopping it completely.

State what would happen if this item or procedure was not approved. Then show how that will lead to additional costs, such as more hospitalizations.

Without the XYZ Valves, Always Denied will continue to vomit and will be at high risk to aspirate or develop aspiration pneumonia and other respiratory complications. She has been hospitalized three times for aspiration and other respiratory complications in the past two years. She also will likely struggle with esophageal damage, tears, and other damage due to daily vomiting; a recent endoscopy already showed damage to her esophagus. Reducing her vomiting will directly reduce the number of hospitalizations for aspiration pneumonia and other complications of frequent emesis such as dehydration, dramatically reducing her medical costs.

Reference your attached medical records in an easily understandable format:

Attached please find several medical documents, as well as information on the XYZ Valve. These include:

- Documentation of vomiting from a recent hospitalization
- Report from endoscopy showing esophageal damage from vomiting
- Report from chest CT showing aspiration damage to the lungs
- Discharge report from a recent hospitalization for aspiration pneumonia
- XYZ Valve brochure

Sum up your arguments, just in case they missed it the first time:

In order to preserve the health of Always Denied and prevent costly future hospitalizations, she needs to receive thirty XYZ Valves per month.

Thank them, even if you don’t want to:

Thank you for attending to this matter.

Sincerely,
Sign here:
Concerned Mother
Lifeline Mailbox  

Consumer Overwhelmed with Diarrhea

On April 2 I underwent an ileorectal anastomosis at Cleveland Clinic. I was told it would be a long recovery, i.e., six months to a year. I am diagnosed with idioopathic intermittent intestinal pseudo-obstruction and the surgeon made it clear that this isn’t a procedure he would generally do on a patient with my medical profile.

My problem now is frequent, hot, burning, watery diarrhea and awful skin eruptions that are painful and tend to bleed. I can’t eat or nibble on anything—except maybe about one-half cup of unseasoned rice or dried beans—without having to make a beeline for the commode. Overnight I have to wear Depends.

The surgeon discharged me with a prescription for Nystatin powder, CCF Butt Paste (containing zinc oxide, corn starch, lanolin, cottonseed oil, bismuth subgallate), and Lotomil (2.5 mg as needed), and I take a scoop of Citrucel daily.

My surgeon told me ahead of time that I should keep “realistic expectations,” but I don’t know what to do about the diarrhea and the eruptions. Anyone out there with any ideas, please let me know.

— Judi Smith judi@intergrafix.net or 570-708-2219

Competitive Bidding, from pg. 1

- Florida — Miami, Fort Lauderdale, Miami Beach
- Florida — Orlando, Kissimmee
- Missouri and Kansas — Kansas City
- North and South Carolina — Charlotte, Gastonia, Concord
- Ohio — Cleveland, Elyria, Mentor
- Ohio, Kentucky, and Indiana — Cincinnati, Middletown
- Pennsylvania — Pittsburgh
- Texas — Dallas-Fort Worth, Arlington
- Puerto Rico — San Juan, Caguas, Guaynabo

The program will be expanded to include seventy additional areas in July 2009.

What To Do

If you feel the program may affect you, initiate a dialogue with your homecare company or provider. They should be able to advise you whether you will be able to stay with your current supplier and to minimize any challenges or confusion related to delivery or access to care and services.

The Oley Foundation staff and trustees, the American Society for Enteral and Enteral Nutrition (A.S.P.E.N.), and other organizations are committed to helping you understand the process and navigate any issues that you may encounter. Please visit www.oley.org for updates or contact us at (800) 776-6539 for printed material. We have also created a link to A.S.P.E.N.’s Web site, www.nutritioncare.org/news/DMEPOS, which outlines all of the details regarding the program and will host a survey to track obstacles, issues, and concerns on your behalf.

Please do not hesitate to contact us with any questions, issues, concerns and unsettling circumstances related to this process. We’re here to help!
A Leap into Spring with Oley Corporate Partners

Joan Bishop, Oley Foundation Executive Director

While welcoming the daffodils and budding trees of spring, Oley Foundation trustees and staff also welcomed the news of a new Platinum Partner ($70,000+). It was heartening to learn that with the Apria/Coram merger there was a coming together of folks who support Oley efforts wholeheartedly. This donation represents a serious leap of faith and a commitment to stand behind efforts that benefit Oley members. We thank Apria Healthcare/Coram Inc., Specialty Infusion Services for continuing to support Oley programs.

This spring Oley trustees and staff also welcomed the news that Nestlé, having recently merged with Novartis, has risen to the Benefactor Partner Level ($10,000+). Again this is a coming together of two companies who have independently supported Oley efforts and who agree that providing funds to help Oley remain in forward-thinking mode is a valuable use of their philanthropic dollars. We are grateful for their generous contributions.

We are also excited to announce that InfuScience, a new homecare company, is celebrating its first anniversary by coming onboard as an Oley Patron Level Partner ($5,000+). Expanding our list of partners helps Oley reach more consumers, and stabilizes our funding.

Generous continuing contributions from all of our sponsors, especially Nutrishare at the Platinum Level ($70,000+) and NutriThrive at the Golden Medallion Level ($50,000+), have allowed Oley to expand and improve its programs. Oley’s online chat forum is off to a fantastic start. And newest on the horizon is the development of MY HPN, an online education tool for consumers to learn how to become more active in their health care and improve their quality of life. By the end of June, module one will be available for consumers, caregivers, and clinicians to try at www.oley.org (see article below).

Use Interactive Web Tool to Improve Care, Quality of Life

Brand new at the Oley Foundation is an online educational tool to help HPN consumers improve their health care and quality of life. Called “MY HPN,” the interactive Web program will have several modules to cover topics from avoiding infection to lab testing to getting off HPN. Module one, which covers strategies for becoming more active in your health care, will be launched by the end of June 2008.

MY HPN can be accessed through www.oley.org. Users are encouraged to provide feedback via the survey at the end. Credit for this incredible undertaking goes to Oley Trustee Cheryl Thompson, PhD, RD, CNSD. Many thanks also to the patient and clinician volunteers who are helping to develop the program.

Equipment/Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Call the Equipment Exchange! Supplies available change daily. At this time we have an abundance of Kangaroo bags—call us! We also want to call attention to the diabetic formulas (Glucerna, Glytrol and renal formulas (Novasource Renal, Peptamen Renal) currently available.

- A full listing of items available for exchange is posted on the Oley Web site, www.oley.org. The listing is updated every week (usually on Mondays), so check frequently. This list includes everything from tubing and bags to formula to durable items.

- You can call Ben (see below) and he’ll see if what you are looking for is in the exchange database.

- Let Ben know what you need, and he’ll contact you if the item becomes available.

Items offered through Equipment Exchange are available free of charge. To offer or claim items, contact volunteer coordinator Ben Hawkins at benhawks@fuse.net or (866) 454-7351 (toll-free). This phone number reaches Ben at home, so please call between 9 a.m. and 9 p.m. EST.

Also, if Ben refers you to someone offering supplies, please follow up with Ben. If you do not take the supplies, he needs to know they are still available; if you do take the supplies, Ben will remove them from the list.

We ask that those receiving goods offer to pay the shipping costs. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition.
Member Profile

Finding Normal, from pg. 1

Polio can attack any part of the body. I was blessed with no limb paralysis, but I couldn’t breathe or swallow. An emergency tracheostomy was my first experience at University of Michigan Hospital, then came the nasal feeding tube. I remember the rubber tubing felt like a garden hose going down. With daily in and out for cleaning, though, the pain eventually subsided. Ultimately, that hose was my ticket home. The doctors decided if I could clean it myself, I could go home; by the end of the day, I could do it.

Two days before Christmas, I was home. Joy and sorrow mingled. My brother’s death was my first personal experience accepting what life deals out. My parents’ strength and love provided a safety net for my younger brother and me.

I finished the school year at home, with help from a retired teacher. The tracheostomy tube had been removed while I was in the hospital, but I still had the feeding tube. At each meal I sat down, chewed my food, and tried to swallow. When it didn’t go down, I spit it into a container. This lasted until August 1950.

“Normal”

Over time, life returned to normal in our blue-collar family and neighborhood. I enjoyed all the usual childhood activities. I was even first chair snare drummer in my high school marching band. Bronchitis stalked me and I choked easily, but I learned how to handle it and recoup. In 1958 (the summer before my senior year), my father’s employer moved from Michigan to Arkansas; my family went along. I graduated from the University of Arkansas, married, lived in Oklahoma City, then moved to Atlanta, where I’ve been for forty-one years.

In 1970, bronchitis almost overcame me until several broncoscopies cleaned years of garbage from my lungs. In 1975 I began graduate school and a career in education. In the 1970s and ’80s, I was wife, mother, graduate student, educator, and community volunteer. Polio had long since been considered history. Survivors had integrated into society. When I became aware of post-polio syndrome in 1990, I discovered I was living out the profile of most polio survivors. We are driven people!

In 1991, becoming an accessibility consultant brought my mission in life and career together, but by 1993 I was experiencing exacerbating fatigue. Faced with choosing between breathing and walking, I began using a wheelchair as well as a BiPap, a noninvasive positive air pressure ventilator. Both enabled me to manage my changing condition.

My husband began helping me with my business, cooking, housekeeping, and driving. I didn’t have the respiratory strength, but I wasn’t concerned about my swallowing. I had long ago learned to manage the choking.

On the day of my father’s funeral in 1999, my husband of thirty-six years had a massive heart attack. We left my father’s Arkansas graveside at noon. By 6 p.m. my husband was dead. All I could hang on to was God, and God protected me. I continued living independently (in a condominium), consulting part-time, writing, drawing, and painting. My pulmonologist continued monitoring my pulmonary function (then in the range of 35-40%). In 2003 I began receiving meals on wheels. After a swallowing study, I started modified meals (chopped). In 2005, chopped went to pureed.

Twin Tubes

In April 2006, I had bronchitis that wouldn’t quit. Breathing and eating became a struggle. I ate yogurt and drank Ensure and V8 juice. After listening to my lungs in May, my pulmonologist had his nurse immediately walk me to the hospital. After another swallowing study, the pureed diet became a clear liquid diet.

Plans were initiated for surgical feeding tube placement. It was also time to talk about a tracheostomy. On Mother’s Day, I had twin tubes placed: an endotracheal tube and a percutaneous endoscopic gastrostomy (PEG) feeding tube, both permanent. I told people the hospital had had a two-for-one Mother’s Day special.

What had caused me to get to this point? The swallowing study showed four to five swallows to get anything down. Even more serious, food and liquid were pooling around my windpipe. The bottom-line was that I had no muscle tone in my pharynx area. My esophagus was described as “floppy.” My airways were in the same condition.

Three days after surgery, the feeding tube started leaking. It was declared okay (twice) and I was discharged (tube still leaking) after a fifteen-day stay. I thought my discharge had come not a minute too soon. I told my pulmonologist we had done our job and it was time for me to go home so I could get well. I was off to find my “New Normal.”

But the next morning I returned for tube replacement in outpatient radiology. The formula leakage was greater than realized, and I had been sent home dehydrated. In replacing the tube, the radiologist inflicted excruciating pain trying to force a size 20 French (Fr) tube into a now smaller track before finally settling on a 16 Fr. The tube had been partially out for so long, the freshly cut track was closing.

This whole process was new to me (I am wondering if it was new to the medical staff, as well!). I hadn’t known what to expect or even what questions to ask. As a result, I will forever deal with a pediatric-size tube, and the resulting slower flow and higher risk of clogging. I’ve also learned that hospitals don’t always have a size 16 Fr. I keep a spare with me at all times, and twice the hospital staff has used mine for a replacement when they did not have one. (Do you know if your hospital or provider always has the equipment size you need?)

I wasn’t finished at the hospital yet. I returned again the next day after a home health nurse clogged my tube by dumping in a dry crushed pill.

“I’m a Survivor”

I had fought a battle to return home and not go to an intermediate care facility, then had to face a barrage of clinical missteps. I saw clearly that surviving was up to me. I’d always believed in taking charge of my health, but my experiences spurred a sense of urgency. I dubbed my trach tube “the good child” and my feeding tube “the unruly child.”
Insisting from the beginning that I be allowed to feed myself, as I began to gain strength I began researching online to learn about the tube and my nutrition. Initially, not knowing the language of tube feeding, I couldn't find information. The hospital had sent me home with none. I learned later that some nutrition manufacturers have free patient booklets that describe tube care, skin care, and nutrition needs.

Truly Unruly

In June, my tube fell out in the surgeon’s hand during a follow-up exam. I was back to radiology for yet another tube placement! By reviewing my hospital records, I discovered later that radiologists were putting 10 cc of saline into a balloon designed for 3 to 5 cc. When the tube fell out again in September, I ended up with a tube with a leaky port. After trying for three days to stop the leakage, I found a solution in my kitchen: a twister tie that had come packed in garbage bags. I crimped my tube and tied the twister tie around it. I do that still.

For me, homemade solutions are often better than trying to get help from professionals. But homemade solutions aren’t always enough. In July, two months after surgery, I developed a large patch of irritation around my stoma. I treated it with antibiotic salve, but it continued to worsen. Before I finally got a home health nurse to check the spot, fungus was having a field day. Nystop powder relieved it quickly. Atlanta, with its hot days, has the perfect climate for fungus folly. Now I use my hair dryer (on low) on both stomas after each cleansing.

Hard to Swallow

The same professionals who just knew I couldn’t take care of myself marveled at my skin and tube care. I shuddered to realize standards I set for myself were higher than standards set by many of my health providers. For me, there is a disconnect between care offered with initial procedures and the quality of ongoing care. I feel we as a community need to change that and insist on consistent quality care.

One thing I just couldn’t accept quietly was the dangling tube. Yet no one suggested safe alternatives until I saw my post-polio specialist, a physiatrist. He suggested the abdominal binder that is now a part of my wardrobe. (See “Tube Talk,” LifelineLetter Jan/Feb 2008.)

From the beginning, my PEG-tube has been my sole pathway for nutrition and fluids. I don’t even swallow my own saliva. (That’s a social challenge! I always carry 8-ounce paper cups, and I’ve learned to expel my saliva while looking like I’m just drinking from the cup. I certainly don’t fill the cup, but have found carrying that size is manageable. Paper is opaque and durable. I take at least four with me everywhere and keep extras in my wheelchair satchel.)

Even though I take no food orally, I continue to brush my teeth just as before. Otherwise a slick film forms over my mouth and teeth. I floss daily. For many years I have brushed with baking soda. My dentist always brags on my oral care. We must care for our general health through attention to daily routines. To stay hydrated, I supplement water with flavorless Pedialyte. (Walmart and Target have their own brands that cost less.)
Pediatric Intestinal Failure Symposium in Pittsburgh

Children’s Hospital of Pittsburgh of the University of Pittsburgh Medical Center has announced the Fifth International Pediatric Intestinal Failure and Rehabilitation Symposium will take place September 11, 12 and 13, 2008, at the Sheraton Station Square Hotel, Pittsburgh, Pennsylvania.

Thursday, September 11, is designed for families and caregivers of children who have intestinal failure and may have had intestinal transplantation. Thursday’s learning session has been designed to enhance the parent/caregivers’ knowledge and understanding of intestinal function. The general medical/surgical session will be on September 12 and 13. Although the presentations offered on these two days will be very scientific in nature, parents and caregivers are invited to attend.

For further information and a brochure please call Jada Shirriel, conference manager, at 412-647-8216 or 412-647-8257. You can also visit the Center for Continuing Education in the Health Sciences Web site at http://cechs.upmc.edu.

If you plan on attending this very exciting symposium and might be available to staff an Oley informational booth, please contact Kate at Oley at 800-776-6359.

HPN Centers of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight institutions that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our consumers strictly as an informational tool. For a listing of other experienced centers visit www.aley.org.

Children’s Healthcare of Atlanta at Egleston/Emory University

The Intestinal Rehabilitation Program at Children’s Healthcare of Atlanta/Egleston/Emory University offers integrated services aimed at reducing PN dependence while optimizing an infant’s growth and development. The program has a multidisciplinary team of gastroenterologists, surgeons, neonatologists, nurses, and dietitians who work together on the care of patients with short bowel syndrome (SBS) and intestinal disorders. The primary goal of this program is to wean patients from PN and improve growth and neurodevelopmental outcomes through in-patient and outpatient programs. There are also active research protocols at the center for patients who wish to participate.

A support group involving families, social workers, and nurses helps families cope with SBS and intestinal failure. The program collaborates actively with the adult nutrition support service at Emory University Hospital. Information about the program can be found at www.pediatrics.emory.edu/divisions/gastroenterology/resource.html.

Update on Nutrition Support Certification

Charles Mueller, PhD, RD, CNSD

The National Board of Nutrition Support Certification (NBNSC) has recently modified its nutrition support certification program. The modifications reflect current nutrition support practice by professionals, including physicians, dietitians, nurses, pharmacists, and physician assistants. The board surveyed a population of such professionals and concluded that the professions overwhelmingly agree that there is a common knowledge and skill set required for the safe and effective management of people receiving parenteral and/or enteral nutrition. Based on this survey, NBNSC has elected to provide one exam to all professionals to qualify them as certified nutrition support clinicians. By virtue of passing the exam, these professionals can use the credential Certified Nutrition Support Clinician or CNSC. The credential is renewable every five years.

Previously, the NBNSC program certified physicians, dietitians, and nurses with different exams using the credentials Certified Nutrition Support Physician (CNSP), Dietitian (CNSD), and Nurse (CNSN). The CNSC credential is being offered to physicians, dietitians, and nurses in 2008, and additionally to pharmacists and physician assistants in 2009. The CNSP, CNSD, and CNSN credentials were also renewable every five years and will remain valid for their full five-year period, after which professionals can renew their certification with the CNSC credential.

Oley members probably know that there are nutrition support health care experts in all of these professions because they have worked with any number of them. The area of nutrition support is one of the first models for interdisciplinary care and practice among health care providers. Indeed, the membership of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) comes from all these professions, and the activities of the society in disseminating practice standards and research findings have long reflected this distinct practice model, whether it be in the form of nutrition support teams or standards of practice that apply to all professionals who practice in nutrition support.

NBNSC is confident that these changes in the certification program reflect actual practice and as such are in the best interest of nutrition support clients in all settings, including the hospital, home, and other long-term care setting.

Dr. Mueller is the president of NBNSC.

Save a Tree

Send us your e-mail address, and we can send you news, the latest conference information, and the LifelineLetter electronically. You’ll save paper and postage, and receive the news well before the postman could deliver it. Our e-mail list is private and will not be shared.

To switch over to an electronic subscription, contact Cathy Harrington at the Oley office at (800) 776-OLEY or harrinc@mail.amc.edu.
Finding Normal, from pg. 11

Personal Resources

After several months with my Twin Tubes, I shed the anxiety from trying to manage foreign objects. But bumps in the road continue to keep me on my toes. The Oley Foundation has helped shatter the unknown. I found Oley during Internet research. To date, only one of my health professionals has known about it. Each of us should make it our mission to provide Oley materials to providers and encourage them to share.

After a year of frustration with my first GI doctor, I found one who is compassionate and skilled. Yet even he is still learning about feeding tubes. A recommendation he made reinforced my stance that I never do something just because a professional suggests it. About a year ago, after yet another tube change, I was having intestinal discomfort, bloating, and diarrhea. I could hold no more than two cans of formula a day. While trying to identify the source of the problem, I switched to this new doctor.

He suggested that a J-tube might alleviate my problem and prevent future issues. I refused and explained that I thought my tube was dislocated. Up to this point, mine had been the voice in the wilderness. But sure enough, that is what the radiologist saw, and the radiologist fixed it in a flash. My new GI doctor said how much he learned from me. Before finding him, I had experienced twenty days of no more than 600 calories a day and had three bags of IV fluids—all because the tube needed a minor adjustment. We must educate ourselves, keep informing our medical professionals, and never silence our strong voice as decision makers on our own behalf.

May 14, 2008, was the two-year anniversary of my new life with Twin Tubes. Challenges are constant, but my quality of life is better. With adequate nutrition and oxygen, I’m stronger. I’ll always remain in my wheelchair, and that’s okay. Life in a wheelchair with a feeding tube and trach is my New Normal. My message to myself when I started using a wheelchair was, “Survivors never quit. We just change our ways!” (© MBL) I claim that daily.

Discount for Oley Members

Cera Products, Inc., based in Columbia, Maryland, manufactures and distributes CeraLyte, a rice-based oral rehydration solution, as well as other products. Oley Foundation members can receive a 15 percent discount on any Cera product when they order through Cera directly. Please identify yourself as an Oley member when placing your order. You can contact the company at (410) 309-1000 or through their Web site, www.ceraproductsinc.com.
Individual Donors—Thank You!

The following list represents everyone who contributed between March 20 and May 28, 2008. We also want to thank all of those who are not listed below, who gave earlier this year or who have supported the Foundation by volunteering their time and talents.

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**In Memory of Marsha L. Kane**

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Sharon Gran
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Norma & Craig Courtois Porter

**Oley Horizon Society**

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at 800-776-OLEY.

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We Appreciate Your Support

Please join Oley in thanking our corporate donors. This issue we highlight:

**Apria Healthcare / Coram Inc., Specialty Infusion Services**

Coram and Apria have merged to create a leading provider of home nutrition services with the goal of exceeding its customers’ expectations every day. With the company’s comprehensive nutrition advantage program, it is dedicated to providing the highest quality clinical care and personal support for both enteral and parenteral consumers. Coram and Apria offer over twenty-five years of experience, home nutrition support teams, consumer advocacy, and the national coverage and local expertise you need.

**Nutrishare, Inc.**

Rod Okamoto and Tom Diamantidis attended their first Oley conference in 1991, the same year that Nutrishare was founded. Nutrishare writes, “The company’s cornerstone principle of focusing exclusively on homePN care and honoring the consumers’ rights to choose their health care providers and the products they use were forged during that remarkable conference in Saratoga Springs, New York, that summer.”

In 2007, Nutrishare, together with the Oley Foundation, launched the Nutrishare Research Prize, designed to recognize and encourage clinical research that will improve the quality of life for homePN consumers and their families. Together, Nutrishare and Oley pioneered Oley’s Platinum Level of corporate support as a tribute to the Oley Foundation’s mission. 2008 will mark Nutrishare’s seventeenth year of caring exclusively for long-term homePN consumers.

**Nestlé HealthCare Nutrition**

For years Nestlé Nutrition has been trusted to provide products that meet special health and medical nutritional needs. Following its 2007 acquisition of Novartis Medical Nutrition, Nestlé’s new, and growing, product portfolio has included a combination of trusted brands from both companies. As one company, known as Nestlé HealthCare Nutrition, it remains committed to providing high quality products to address evolving health care needs with proven results.

Nestlé HealthCare Nutrition’s enteral product solutions help optimize the nutritional intake of consumers and patients while supporting prescribed medical treatments. Whether a patient needs to combat disease, recover more quickly, or maintain their health, Nestlé HealthCare Nutrition provides quality nutrition products to those with special needs, in every stage of life. Nestlé’s heritage and global leadership in the food and beverage market has given it the ability to touch the lives of consumers in every continent on the globe. Nestlé HealthCare Nutrition is the second-largest health care company in the world.

**InfuScience, Inc.**

As the “next generation of comprehensive infusion providers,” InfuScience is proud to be an Oley partner. Utilizing decades of experience from leaders in the infusion industry, InfuScience excels in the delivery of nutrition services, antibiotic, and other infusion therapies in the home. The InfuScience team is dedicated to exceeding its customer’s needs while providing optimal patient care, education, and support. Maintaining high standards in the delivery of infusion therapy allows InfuScience to provide a valuable experience to customers. Visit www.infuscience.com to learn more about the company’s commitment to serving patients with integrity, quality, and accountability.

**Baxa Corporation**

Baxa develops devices and systems for safe and efficient preparation, handling, packaging, and administration of fluid medications. The company’s Exacta-Mix™ and MicroMacro™ automated compounders safely mix parenteral nutrition solutions for home and hospital use. Baxa compounders are automated systems that accurately deliver both macro and micro ingredients in a single unit, with bar code ingredient verification to eliminate medication errors. These systems represent the state-of-the-art for nutritional support.

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**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.

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($70,000+)

- Apria Healthcare / Coram Inc., Specialty Infusion Services
- Nutrishare, Inc.

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- Sigma International

**CONTRIBUTORS**

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- Baxa Corporation
- Zevex, Inc.
### Toll-Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the United States and Canada. Two toll-free numbers are circulated to experienced homePEN consumers on a monthly basis. The goal is to make speaking with fellow lifeliners more affordable, and to provide Oley's Regional Coordinators with a better grasp of their region's needs.

Advice given by volunteer coordinators represents the experience of that individual and should not imply endorsement by the Oley Foundation.

Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 30 minutes.

The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter, and posted at www.oley.org. Comments? Call (800) 776-OLEY.

<table>
<thead>
<tr>
<th>Toll-Free Schedule</th>
<th>JULY '08</th>
<th>AUG. '08</th>
<th>SEP. '08</th>
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| **Chuck Lindley**  | Burlington, NC  
(888) 610-3008 EST | **Rosaline Wu**  
Livonia, MI  
(888) 650-3290 EST | **June Bodden**  
Clearwater, FL  
(888) 650-3290 EST |
| **Carol Pelissier** | Manchester, NH  
(888) 610-3008 EST | **Carla Truman**  
Phoenix, AZ  
(888) 650-3290 MST | **Felice Austin/ Mariah Abercrombie**  
Henderson, NV  
(888) 610-3008 PST |
| **June Bodden**  | Clearwater, FL  
(888) 650-3290 EST | |

**Chuck Lindley** is a hospital pharmacist and the father of Mason, who suffered an accident that left him HPEN dependent and with an ileostomy. Mason passed away in 2005, but his legacy continues through the Mason Lindley Miracle Foundation, which supports children and families facing medical challenges through music.

A lifetime of abdominal problems and nearly twenty years of HPN have led Rose and her husband, Bill, to take each new day as a gift. Rose and Bill benefit from a strong family of lifeliners in their area and try to keep them connected. They have attended several Oley conferences and have traveled with HPN. Rose was the first recipient of the Lenore Heaphey Grassroots Education Award in 1994.

**Carol Pelissier** underwent a total colectomy due to colonic inertia, malabsorption, and chronic intestinal pseudo-obstruction. She began HPEN in 1995. She has an ileostomy and has endured over 44 surgeries. She is determined to ensure that people are not alone and to help others cultivate a positive attitude.

**Carla Truman’s** son Billy, now 21, was on HPEN since birth due to SBS. After a successful small bowel transplant in May 2007 he uses HEN only as a supplement for calories. Carla also has experience with school systems and IEPs as Billy has other special needs as well.

**Mariah Abercrombie** is a 26-year-old college student; she’s been on PN since 1985 due to pseudostomalation and now short bowel. She also has a G-tube and an ileostomy. She works as a nanny and enjoys many activities and hobbies. She is comfortable talking to young adults and parents.

**Felice Austin** is a single mother and former social worker. She was Mariah’s caregiver and has been an Oley RC since the late 1980s.

**June Bodden** has had Crohn’s disease since age 15, an ileostomy since age 21, and has been on PN since age 39 (over 23 yrs., 14 hrs. every day). An Oley RC and an active support group member, June believes networking with others is important. A strong faith, volunteer work, and help from family and friends keep June upbeat.