CDC Guidelines on Preventing Catheter-Related Infections

In 2011, the Centers for Disease Control (CDC) updated their “Guidelines for the Prevention of Intravascular Catheter-Related Infections.” The guidelines, which replace those issued in 2002, were developed for everyone involved in the placement and care of central venous catheters (CVCs) in any setting (i.e., hospital, outpatient, and home). At eighty-three pages, the complete report is obviously too long for us to reprint here. Also, the guidelines cover intravascular catheters used for many purposes (beyond parenteral nutrition) and in all kinds of settings (including the ICU), and only some of the recommendations pertain specifically to home parenteral nutrition (HPN) consumers and caregivers. We have pulled out the recommendations we think would be of most interest to HPN consumers and list them below.

You can use some of these recommendations at home (such as guidelines for care), but we’ve also included some that are directed specifically to health care providers. We hope these will help you as you are faced with decisions or as you talk to your health care providers. Maybe some will raise questions you’d like to bring to your next appointment. Please note that in a few cases, Oley medical reviewers have felt some clarification on how these guidelines apply to homePN consumers is necessary; their comments are Infection Guidelines, cont. pg. 9 ☛

Thorough hand washing is critical for catheter care.

Being a Good Patient

Jenn Wright

I have been on home parenteral (or IV) nutrition (HPN) since 2004, when I was diagnosed with profound gastroparesis. I was also on home enteral nutrition (HEN, or tube feeding) for a short time. I had both a G-tube (for decompression) and J-tube (for medications) for over four years. In August of 2010 I had a total gastrectomy, as my gastric tube sites were chronically infected—a constant threat to my HPN central line. Despite the gastrectomy, a combination of further health and dysmotility issues means I am a permanent HPN consumer.

Being a Good Patient, cont. pg. 2 ☛

Drug Shortages: New Bill Proposed

Senator Amy Klobuchar (D-MN) hosted a panel discussion on access and affordability of prescription medications in January. Drug shortages have tripled since 2005, affecting the public’s access to critical medications. The shortages have affected many components of parenteral nutrition (PN) solutions, including trace elements and vitamins. Shortages can be influenced by a lack of raw materials, financial decisions by pharmaceutical companies, and regulatory barriers which slow production but don’t improve product safety.

The panel also addressed affordability. All too frequently, brand name drug manufacturers will pay significant sums to generic drug manufacturers to delay availability of less expensive options. This is expected to increase the cost of Medicare by as much as $2.6 billion

Drug Shortages, cont. pg. 5 ☛
Being a Good Patient, from pg. 1

This article contains some of the wisdom I've gleaned about being a good patient. Don't Wait

Know your body. Listen to it carefully so you know when something just doesn't feel right, because only you can know. Practice putting into words what doesn't feel normal.

Particularly for HPN patients: never postpone getting evaluated and/or treated for a fever, especially if it is accompanied by shaking chills. If you have a fever, call the doctor who manages your HPN; he or she will order blood tests and blood cultures to decide if an emergency room visit is appropriate. Many doctors recommend 101° or 101.5°, but waiting for a temperature to spike that high may be the difference between a central line infection with sepsis (widespread bloodstream infection) and the onset of septic shock, which is life-threatening.

I've never been dismissed as melodramatic or overly cautious for visiting the emergency room with a fever of 100.5°, and since many alternative-nutrition patients are subject to lower average body temperatures, 100.5° can be a significant fever. For instance, my normal body temperature hovers around 97.2° to 97.6°; comparatively speaking, that would equate to a person whose normal temperature is 98.6° having a fever of 101.1° to 101.5°—high enough to warrant a visit to the ER.

Take Care of Skin

For HEN patients, take gentle care of all tube sites. Don't wait until there's a problem before paying attention to them. Skin breakdown and infection can spread rapidly and/or turn into something worse (cellulitis, peritonitis, and so on). Keeping tube sites protected with a barrier cream helps; mix in some lidocaine 2% gel or EMLA cream, and you've got anaesthetic (anesthetizing) plus moisture barrier. Anything unusual that might indicate a problem should be watched and a doctor or home health care nurse contacted if necessary.

Be Prepared

Keep a current list of your allergies and medication regimens. The patient travel/hospital pack on the Oley site is by far the best way I've found to keep my medical information current (download it from www.oley.org/travelpack.html or request a copy by phone, 800-776-OLEY). In addition, I keep a current copy of my medication regimen, including all medications with correctly spelled names (both generic and patented/trade names), dosage, route (IV, J-tube, or oral), indication, and frequency/PRN, as well as a list of all my doctors, their specialties, and their phone numbers.

While many medical centers (associated hospital and outpatient clinics) ostensibly share a single medical record/medication list for both inpatient and outpatient visits, I've rarely found this to be accurate. I've found that the Oley form as well as my personally kept lists of medications and doctors drastically reduce the time it takes for the medications and specialists I need to be on hand when I need them, should I be hospitalized. This information is especially crucial if you need medical help while out of town.

Prepare a bag for when you may be hospitalized. Include a current copy of all your medical information (as recommended above). Consider including your own bathrobe; a pair of non-slip socks or slippers; your own pajamas (many hospitals allow patients to wear their own clothing); travel-size toiletries (let's face it—hospitals are not handing out Bath and Body Works™ samples for their soaps and lotions); a small blanket or quilt that will make your bed a little more homey; and anything that might help pass the time.

Find a Good Doctor

Find a primary care physician (PCP) whom you can trust and with whom you can be blatantly honest. If your doctor doesn’t meet your needs, give you enough time to address your concerns, or seem capable or willing to make the complexities of your condition(s), find one who does. My PCP gives me a double-time appointment (my medical chart notes that all appointments are double slots), and we meet every six weeks no matter what, with in-between visits as necessary. This way he can keep up-to-date with all of my issues and make med changes, referrals, and recommendations whenever necessary. [Editor’s note: If you are a well-established HPN patient and you don’t have any known problems, you won’t need to meet with your doctor so frequently. For the first six months on HPN, a visit every six weeks is appropriate; for the second six months, a visit every eight weeks should be OK; and after a year on HPN, if you aren’t experiencing any problems, a visit every three or four months is reasonable.]

Be assertive and truthful with your health care providers so they can thoroughly partner with you. Even if you aren’t 100 percent compliant (is anyone?), be honest. A good doctor will understand that sometimes circumstances necessitate a change.

Prepare for all appointments with physicians, PAs, ARNPs, nutritionists, etc. Keep a running list of concerns to discuss at your next appointment and write your questions in your medical chart notes (both generic and patented/trade names), dosage, route (IV, J-tube, or oral), indication, and frequency/PRN, as well as a list of all my doctors, their specialties, and their phone numbers.

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Tube Talk

Send your 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.

Pocket Secures Tubes

My daughter, now thirteen years of age, was born with a motility disorder. As a result of her condition, she had a gastrostomy/jejunostomy (G-J) feeding tube placed as a young infant. She has also required a central line for six consecutive years for added nutrition.

Early on, I grew apprehensive of the tubes and lines hanging freely from my little girl's torso, feeling many complications could easily occur. I was fearful of her tubes and lines unintentionally getting yanked when we picked her up or changed her clothing. I was also distressed about my daughter curiously tugging on them herself. Despite my efforts to avoid the unavoidable, these things did happen periodically.

Once she started crawling, my concerns heightened. I tested various methods to secure the tubes and lines. For starters, I taped them to her skin, but this only replaced a problem with a problem—the outcome was skin irritation and blistering. Afterwards, I pinned the hanging attachments to her clothing, but I was worried I would not remember to unpin them before removing her clothing.

Soon enough, I constructed a wearable pouch to keep her tube and line safe up against her torso, but separate from both her clothing and skin. My daughter began wearing my creation and immediately fell in love. She wore this pouch twenty-four–seven and before long she nicknamed it “my pocket.” After seeing her “pocket,” the staff at Beaumont Children's Hospital began to urge me to make this available to all patients with feeding tubes and central lines. MyPokit became my passion.

MyPokit is made of comfortable, washable fabric and can be worn discreetly underneath clothing while keeping your feeding tube or central line safe. MyPokit is available in various styles and will soon be available in a slightly different design aimed towards the adult. Visit www.mypokit.com to learn more.

Tuck tubing in to MyPokit when it isn’t needed.

—Melissa Saville
Melissa@mypokit.com
Summer Camp: Center for Courageous Kids, and more!

Dana Beech

Camp is a fun part of summer for thousands of children each year, but for our son who has complex special needs, we thought this was one experience he would miss out on. As parents, we fondly remembered our own summer camp experiences—the days filled with swimming, horseback riding, fishing, campfires, and building friendships that lasted a lifetime. We knew that traditional summer camps were just not designed to meet Chase's physical, emotional, and medical needs. We never imagined that there was a camp that could provide a comforting and physically accommodating experience for families with children who have special needs. That all changed once we were introduced to the Center for Courageous Kids.

We did our research and knew it was the type of camp we wanted—a medical camp that welcomed our medically fragile child and had medical staff ready to support us if a need were to arise while he was at camp. We were fortunate that they offered family retreat weekends, where we were allowed to attend camp as a family. It was a re-energizing, re-focusing, and rejuvenating experience. After spending so much time in the hospital, it was the first time we could really just enjoy being a family. There were no stares or intrusive questions—everyone at camp had the same tubes, lines, and medical issues.

The camp also provided a one-on-one volunteer who not only helped things go more smoothly, but who also made Chase feel very special. Our volunteer, Desiree, was definitely a godsend and we will never forget her. Chase had the opportunity to participate in activities that aren’t possible for him to do at home. It was an incredible, life-changing experience that had us all in tears as the weekend drew to a close. We loved our time at CCK. It is an excellent program run by dedicated and compassionate individuals. Chase wishes he could have stayed forever.

Details on CCK and Other Camp Opportunities

- **Center for Courageous Kids, Scottsville, Kentucky**
  
  Tube Dependent/TPN Family Retreat Weekend, April 13–15. For campers aged 3–17 (and their families).
  
  Overnight Summer Camp, July 3–7. For campers aged 7–15 with physical disabilities (feeding tubes okay).
  
  Applications available at www.courageouskids.org or by calling the Office of Camper Recruiting, (270) 618-2912. No charge to families or campers. Questions? Contact Faith Carey, (270) 618-2902.

- **Camp Chihopi, Children’s Hospital of Pittsburgh**
  
  For campers aged 7–15 who’ve had liver and/or intestinal transplants or have been evaluated for transplant. August 10–13. Deadline for applications is June 1. Details and applications at www.chp.edu/CHP/camp-chihopi. Questions? Contact Beverly Kosmach-Park, DNP, (412) 692-6115.

- **Double H Ranch, Lake Luzerne, NY**
  
  Sessions throughout the summer. Contact information: (518) 696-5676 or www.doublehranch.org.

- **Painted Turtle, Lake Hughes, CA**
  
  Liver Disease and Transplant, Primary Immunodeficiency Diseases, and TPN Summer Camp, August 8–12. For campers aged 7–16.
  
  Questions? Contact Rosalyn Skeleton, (661) 724-1768, or visit www.thepaintedturtle.org.

We’d love to hear about your experiences or learn about other camp opportunities. Please contact Lisa Metzger at (800) 776-6539 or metzgel@mail.amc.edu.

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**Equipment-Supply Exchange**

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Check out the Oley Foundation’s Equipment-Supply Exchange at www.oley.org! The list of items available is updated every Monday.

Questions? No Internet access? Contact Oley volunteers Tammi and Rob Stillion at Oleyequipment@aol.com, or call toll-free, (866) 454-7351, between 9 a.m. and 4 p.m. EST.
Drug Shortages, from pg. 1

over the next ten years. This practice is considered to be a violation of federal antitrust law. Chairman of the Federal Trade Commission, Jon Liebowitz, participated on the panel and called this the “most abusive practice in health care today.” These “pay for delay” arrangements can further aggravate overall drug shortages and affordability of needed medication, according to Stephen Schondelmeyer, an expert in pharmaceutical economics and another member of the panel.

Oley members Harlan Johnson; Darlene Kelly, MD, PhD; Joe Nadeau, BS, RPh; Mary Patnode; and Elizabeth Tucker attended the panel discussion in Minneapolis, Minnesota, on January 12, 2012.

New Bill Introduced

Also in January, U.S. Representatives John Carney (D-DE) and Larry Bucshon (R-IN) introduced “The Drug Shortage Prevention Act.” This new bill (HR 3839) mandates expedited review of drugs vulnerable to shortage in order to prevent shortages in the first place and it requires the FDA to use a more refined regulatory process that addresses manufacturing problems without instigating drug shortages. The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) is endorsing this bill.

Senator Klobuchar has also sponsored federal legislation—S. 296, “Preserving Access to Life-Saving Medications”—to address the issues of access and affordability. This past year she helped move S. 296 through the Senate Judiciary Committee. The legislation continues to move through the Senate. You may have already read about this bill—and its companion bill, HR 2245, “Preserving Access to Life-Saving Medications Act of 2011”—in this newsletter.

It’s also worth noting that in October, President Obama issued an executive order aimed at resolving the growing number of shortages. This action is an acknowledgment that the administration is taking drug shortages seriously.

What can you do? Contact your U.S. Senators and Representatives to let them know the importance of these bills to your health and survival. (Sample letter at www.oley.org/sample_letters.html.) In the past two years, every component of HPN, except water, has been in short supply, and each component is absolutely essential for the maintenance of your health and your survival. Also, ask your home infusion companies to let their other clients know that this approach might impact the effectiveness of this legislation. Together we can really make a difference with this issue.

—Mary Patnode, with Oley staff

Editor’s Note: To read detailed information about the current legislation and how the shortages are affecting consumers, go to www.oley.org.
Being a Good Patient, from pg. 2

advance. I have a small notebook dedicated specifically to questions for my medical team, and I carry it to all my appointments, with a pen to write down the answers. Don’t be afraid to ask questions. Remember that you are not inferior just because they are authorities in their fields of practice. You are the captain of your medical team; the health care providers are all parts of your team, but you’re the one in charge. Just remember you’re working with a team of people—sometimes many people—and each one is human and therefore capable of making errors in judgment, seeming insensitive, or making a mistake. Your responsibility is to rally the team together as cohesively as possible, and make sure you’re a part of all the decisions being made.

Know Your Diagnosis

Educate yourself about your condition(s). Being educated about your health doesn’t just help you; it helps those who are helping you. When I was first diagnosed with gastroparesis, I went online and found G-PACT and a Yahoo! forum. I also found several medical sites that offered current information about treatments and clinical trials for medications and medical technology, including a motility medication available in Canada and a device that was being tested in diabetic patients with gastroparesis.

Likewise, when I found out I had severe osteoporosis, hyperparathyroidism, and a rare sleep disorder, I educated myself through my doctors, the Internet, and printed resources to make sure I could knowledgeably discuss issues with my multiple specialists. By researching my conditions, I am able to meet my doctors with information and educated questions, which (while saving time) aptly conveys my intention to be a part of the decisions being made about my health care. [Note: Not all resources are accurate and reliable. Be selective about which resources you trust.]

Be Congenial

Be a good hospital patient. No one enjoys being sick or hospitalized, but you can make it easier on yourself by making it easier on the staff. Call your nurses and assistants by their names. Say “please” and “thank you.” Ask for medications in advance, so the staff has time to get them before it’s urgent. Nurses are incredibly overworked, and can often seem insensitive. Think of a way to encourage them while they take care of you—you’ll be surprised how far fundamental good manners and a compliment can go. Also, ringing the nurse call every thirty minutes doesn’t endear you to the nursing staff. If possible, wait until you have more than one reason to call for assistance—it can radically minimize the time they spend traveling in and out of your room.

Understand Your Insurance

Learn the ropes of your health insurance, your hospital/health clinic, and home health care support. Educating yourself makes everything move more smoothly. When you find a good customer service representative with your insurance provider, ask for his or her name and extension, and use him or her as a contact whenever you have a question. This allows shorter calls and streamlines the process when issues arise. Likewise, find out how you can best provide your home health care agency with your supply request (if needed). I asked my suppliers what would be easiest, and now I send them an e-mail every Monday with an attached document form I created that lists anything I could possibly need and in what quantities. This way they don’t have to chase me down, and all I have to do is plug numbers into my request form. It may take a few minutes to make an original document, but overall it saves time and trouble for both you and your supplier.

Live!

Choose to be a person with chronic illness, not a chronically ill person. Your illness is not your identity unless you let it be—and that’s the fastest route to loneliness, isolation, depression, and frustrated/exasperated physicians. Be you—an ordinary person whose health may not be ordinary, but who has chosen to be courteous and positive in the face of extraordinary circumstances.

Live up to your limitations. Be wise and use common sense, but don’t stop living! My husband and I have spent six days rafting the Colorado River in the depths of the Grand Canyon; traveled to Scotland; cruised; traveled nationally; and will be returning to Scotland to celebrate our fortieth and fiftieth birthdays—all with HPEN. I may be somewhat fragile health-wise, but I’m going to enjoy everything I can while I am able.

Traveling may be more complicated when HPEN is a factor, but don’t let embarrassment or other concerns stop you. Airport personnel are usually very understanding and discreet if you are courteous and offer information about any carry-on items that may be on the restricted list. Be sure to carry a letter from your doctor and/or your home health care agency; request it in advance to give them plenty of time to prepare it (many home health care agencies have a form letter you can personalize for such occasions). Also, medical supplies shouldn’t be considered baggage; contact your airline in advance for instructions about how to avoid extra luggage charges.

PS.

Never stop learning… ¶

National Healthcare Decisions Day, April 16

It isn’t always easy to think about the future. But being prepared for what eventually lies ahead for all of us can give us peace of mind and ensure that our loved ones and health care providers understand our wishes.

National Healthcare Decisions Day was established to “inspire, educate, and empower” both the public and health care providers in regards to advance care planning. “It is an initiative to encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be.”

Use April 16 to consider your advance care planning. Go to www.nhdd.org for more information and a wealth of resources.
Center 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 readers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org or call (800) 776-OLEY.

The Intestinal Rehabilitation Center, Children’s Mercy Hospital, Kansas City, Missouri

The Intestinal Rehabilitation Center at Children’s Mercy Hospital in Kansas City offers nutritional care to children with intestinal failure. The center is the product of the collaboration of the Department of Pediatric Gastroenterology and Pediatric/Transplant Surgery. The multidisciplinary team consists of pediatric specialists with experience in the care and management of patients with short bowel syndrome and intestinal disorders.

The center provides both medical and surgical therapies to these groups of individuals. Their team consists of gastroenterologists, pediatric surgeons, nurse practitioners, a dietitian, a pharmacist, a social worker, and a psychologist. Joel Lim, MD, is the Medical Director, and Richard Hendrickson, MD, is the Surgical Director. The program can be reached by calling (800) 806-8544.

Mailbox

Equipment-Supply Exchange Program Volunteers Make an Impression

To show my immeasurable gratitude to the Oley Foundation for the lifeline it has been—I am included in the thousands who have been served with dignity and respect.

I also must thank Tammi Stillion by name, who I have had the pleasure of speaking with countless times. I have never left a conversation with Tammi without knowing I was speaking to a friend. Those moments live in a person’s heart forever.

—Jessica Schulman
Smithtown, NY

This note of appreciation and enclosed donation are in large part thanks for being able to access your “supplies available” page (Equipment-Supply Exchange), as ably managed by Tammi and Rob Stillion. With their help I was able to access the product I needed to supplement my nutrition needs for a thankfully short period of time until my short gut recovered.

Thanks again for your good works and many volunteers who work diligently to meet the needs of others.

—Howard Goldmacher
Chase Roswell, GA
Real People Discuss Life with an Ostomy

Book Review by David McGee

Brenda Elsagher, comedienne, author, and public speaker, has written four books. The most recent book, It’s in the Bag and Under the Covers, is groundbreaking, with stories of people with ostomies talking about dating, sex, intimacy, and caregiving. They reveal an honest look at a previously taboo subject. These are real stories by real people—always hoping to help someone who is new to living life with an ostomy—about subjects they have rarely, if ever before, spoken of. There is heartbreak, as well as triumph, and everything in between.

Maybe you need some ideas on how to tell your date you have an ostomy or maybe you just want to see how other people handle intimacy. It’s all here for you to read. There are over sixty stories; some are a couple of paragraphs long, others a couple of pages. Also, sixty-plus contributor biographies (many complete with e-mail contacts) are included. My wife and I met over a dozen of these “fellow contributors” at this year’s United Ostomy Associations of America (UOAA) conference, so I can verify they are real people! (My story is on page 7.)

Brenda’s first book, If the Battle Is Over, Why Am I Still in Uniform?, is based on her experience with colorectal cancer at age thirty-nine. Brenda uses irreverent humor to cope with the devastating news of a colostomy, and she tells her story openly and honestly. As you read, you are likely to find yourself truly laughing out loud (lol).

Her second book, I’d Like to Buy a Bowel Please!, came about after she got to know hundreds of people who had suffered with bowel diseases, such as Crohn’s and ulcerative colitis, along with bladder and colon cancers. These stories are also filled with humor and hope, as well as a slice of daily life with an ostomy. You’ll also get educated on the reasons people need an ostomy, and how this drastic surgery has been not only a lifesaver, but a life-enhancer for many.

Bedpan Banter is Brenda’s third book. It is a compilation of medically related stories from nurses, doctors, patients, and caregivers. We all know someone who’s faced a medical issue; at some point in our lives that someone will be us, and at other times, we will want to help another in their situation. This book is a celebration of people and their ability to laugh during difficult times. It is truly a survival guide to accepting life’s challenges.

All four books are available through Brenda’s Web site, www.livingandlaughter.com. It’s in the Bag and Under the Covers is $16.95, including shipping (within the U.S.).
Infection Guidelines, from pg. 1

noted with asterisks or another symbol (†) and appear at the end of the article and in Table 1.

Note that in providing just a summary of just some of the recommendations, we are omitting a lot of interesting and important information contained in the report, including the background information explaining the “why” behind the recommendations. If you take the opportunity to review the complete report (available on the CDC Web site, at www.cdc.gov/hicpac/BSI/01-BSI-guidelines-2011.html), please remember that many of the guidelines were developed for use in critical care or are applicable in hemodialysis or with chemotherapy. The needs and circumstances of these patient populations differ from those of the HPN consumer. For example, their length of time with a CVC may be much shorter and thus long-term access may not be an issue; a CVC used for the administration of chemotherapy drugs may not be as susceptible to some infections as a CVC used for nutrient-rich PN; and, of course, what applies in the hospital often doesn’t apply at home. [Editor’s note: For more information on preventing catheter-related infections, check out the Oley Foundation’s free, interactive MY HPN program online at www.oley.org /Education_Module1.html.]

Introduction

The guidelines are intended to provide evidence-based recommendations for preventing intravascular catheter-related bloodstream infections (CRBSIs). They were prepared by a working group led by the Society of Critical Care Medicine (SCCM). Included in the long list of collaborators are the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), the Infusion Nurses Society (INS), and the CDC. Other professional organizations also represent these disciplines, as well as infectious disease, health care infection control, surgery, anesthesiology, interventional radiology, pulmonary medicine, and pediatric medicine. The guidelines are truly a multidisciplinary effort.

HomePN Research Prize: Apply for $2,500 Award

Don’t miss this opportunity to gain recognition for your homePN research, and win thousands in prize money! Apply for an Oley Foundation 2012 HomePN Research Prize, sponsored by Nutrishare, Inc.

Oley will award $2,500 for each of the top three clinical papers dedicated to helping parenteral nutrition consumers. A portion of each prize ($1,000) will be toward travel expenses to bring the winning recipients to the Oley Conference in Redondo Beach, California, June 25–29, 2012, where they will present their research.

Details on the award criteria and application process are available at www.oley.org or by calling (800) 776-6539. Many thanks to Nutrishare, Inc., for sponsoring the award.

Hurry! Deadline for submissions is April 2.

Maximize Health!
Short Bowel Rehabilitation at Home

ThriveRx is expanding our successful Maximize Health! Program to incorporate a personalized approach to our Short Bowel education and training. This program includes:

• Comprehensive clinical assessment
• Individualized diet counseling
• Central Venous Access education
• Medication review
• Strategies to avoid long-term complications

ThriveRx consumers enrolled in this personalized approach to care, have shown reduced output, improved hydration, weight gain, reduction in Parenteral Nutrition requirements and an improved Quality of Life.

Please join our free webinar “Short Bowel Syndrome and the Power of Intestinal Rehabilitation” live on March 8th at 12 noon EST, or view the recorded session at www.thriverx.net

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Volume XXXIII, No. 1

(800) 776-OLEY • LifelineLetter — 9
Infection Guidelines, from pg. 9

Classifications
Each recommendation is categorized as follows:
- IA. Strongly recommended for implementation and strongly supported by well-designed studies.
- IB. Strongly recommended for implementation and supported by some studies and a strong theoretical rationale; or an accepted practice (e.g., aseptic technique) supported by limited evidence.
- IC. Required by state or federal regulations, rules, or standards.
- II. Suggested for implementation and supported by suggestive studies or a theoretical rationale.
- Unresolved issue. Evidence is insufficient or no consensus regarding efficacy exists.

The Recommendations

Education, Training, and Staffing
- Periodically assess knowledge of and adherence to guidelines for all personnel involved in the insertion and maintenance of intravascular catheters. Category IA
- Designate only trained personnel who demonstrate competence for the insertion and maintenance of peripheral and central intravascular catheters. Category IA
- Ensure appropriate nursing staff levels in ICUs. Observational studies suggest that a higher proportion of “pool nurses” or an elevated patient-to-nurse ratio is associated with CRBSI in ICUs where nurses are managing patients with CVCs. Category IB

Selection of CVC Catheters and Sites
- Use a CVC with the minimum number of ports or lumens essential for the management of the patient. Category IB
- Promptly remove any intravascular catheter that is no longer essential. Category IA

Hand Hygiene and Aseptic Technique
- Perform hand hygiene procedures, either by washing hands with conventional soap and water or with alcohol-based hand rubs. Hand hygiene should be performed before and after palpating catheter insertion sites as well as before and after inserting, replacing, accessing, repairing, or dressing an intravascular catheter. Palpation of the insertion site should not be performed after the application of antiseptic, unless aseptic technique is maintained. Category IB
- Maintain aseptic technique for the insertion and care of intravascular catheters. Category IB
- Wear either clean or sterile gloves when changing the dressing on intravascular catheters. Category IC

Catheter Site Dressing Regimens
- Use either sterile gauze or sterile, transparent, semipermeable dressing to cover the catheter site. Category IA
- If the patient is diaphoretic [or sweating excessively] or if the site is bleeding or oozing, use a gauze dressing until this is resolved. Category II
- Do not use topical antibiotic ointment or creams on insertion sites, except for dialysis catheters, because of their potential to promote fungal infections and antimicrobial resistance. Category IB
- Do not submerge the catheter or catheter site in water. Showering should be permitted if precautions can be taken to reduce the likelihood of introducing organisms into the catheter (e.g., if the catheter and connecting device are protected with an impermeable cover during the shower). Category IB
- Replace transparent dressings used on tunneled or implanted CVC sites no more than once per week (unless the dressing is soiled or loose), until the insertion site has healed. Category II
- No recommendation can be made regarding the necessity for any dressing on well-healed exit sites of long-term cuffed and tunneled CVCs. Unresolved issue

Table 1. Catheters used for venous and arterial access.

<table>
<thead>
<tr>
<th>Catheter Type</th>
<th>Entry Site</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nontunneled central venous</td>
<td>Percutaneously inserted into central veins (subclavian, internal jugular,</td>
<td>Account for majority of CRBSI</td>
</tr>
<tr>
<td>catheters</td>
<td>or femoral)</td>
<td></td>
</tr>
<tr>
<td>Peripherally inserted central</td>
<td>Inserted into basilic, cephalic, or brachial veins and enter the superior</td>
<td>Lower rate of infection than nontunneled CVCs</td>
</tr>
<tr>
<td>venous catheters (PICC)</td>
<td>vena cava</td>
<td></td>
</tr>
<tr>
<td>Tunneled central venous</td>
<td>Implanted into subclavian, internal jugular, or femoral veins</td>
<td>Cuff inhibits migration of organisms into catheter tract; lower rate of</td>
</tr>
<tr>
<td>catheters</td>
<td></td>
<td>infection than nontunneled CVC</td>
</tr>
<tr>
<td>Totally implantable [port]</td>
<td>Tunneled beneath skin and have subcutaneous port accessed with a needle;</td>
<td>Lowest risk for CRBSI; improved patient self-image; no need for local</td>
</tr>
<tr>
<td></td>
<td>implanted in subclavian or internal jugular vein</td>
<td>catheter-site care; surgery required for catheter removal†</td>
</tr>
</tbody>
</table>

† Oley Medical Reviewer Note: Lowest risk for CRBSI is true for chemotherapy studies; other research has shown no difference in infection rate for ports vs. tunneled catheters in HPN use. Surgery would be required for port repair as well.
• Ensure that catheter site care is compatible with the catheter material. Category IB
• Monitor the catheter sites visually when changing the dressing or by palpation through an intact dressing on a regular basis, depending on the clinical situation of the individual patient. If patients have tenderness at the insertion site, fever without obvious source, or other manifestations suggesting local or bloodstream infection, the dressing should be removed to allow thorough examination of the site. Category IB
• Encourage patients to report any changes in their catheter site or any new discomfort to their provider. Category II

** Catheter Securement Devices
• Use a sutureless securement device to reduce the risk of infection for intravascular catheters. Category II**

*Systemic Antibiotic Prophylaxis
• Do not administer systemic antimicrobial prophylaxis routinely before insertion or during use of an intravascular catheter to prevent catheter colonization or CRBSI. Category IB

**Antibiotic Lock Prophylaxis, Antimicrobial Catheter Flush, and Catheter Lock Prophylaxis
• Use prophylactic antimicrobial lock solution in patients with long-term catheters who have a history of multiple CRBSI despite optimal maximal adherence to aseptic technique. Category II

Replacement of CVCs, Including PICCs
• Do not routinely replace CVCs or PICCs to prevent CRBSIs. Category IB
• Do not remove CVCs or PICCs on the basis of fever alone. Use clinical judgment regarding the appropriateness of removing the catheter if infection is evidenced elsewhere or if a noninfectious cause of fever is suspected. Category II***

**Needleless Intravascular Catheter Systems
• Ensure that all components of the system are compatible to minimize leaks and breaks in the system. Category II
• Minimize contamination risk by scrubbing the access port with an appropriate antiseptic (chlorhexidine, povidone iodine, an iodophor, or 70% alcohol) and accessing the port only with sterile devices. Category IA
• Use a needleless system to access IV tubing. Category IC
• When needleless systems are used, a split septum valve may be preferred over some mechanical valves due to increased risk of infection with the mechanical valves. Category II

Report any changes in...
catheter site or any new discomfort to [your] provider.

Notes from Oley medical reviewers:
*This should apply to any nursing unit that deals with CVCs.
** Stat locks [sutureless securement devices] only work with PICCs and Power Hickmans. The device is needed for the life of the PICC and until the Hickman cuff becomes anchored. It cannot be used in a silicone Hickman (which is often the preferred long-term device) because that CVC does not have the adapter molded in the catheter like the PICC and Power Hickman. If you have a tunneled cuffed central line, the stitch should be removed in approximately four weeks since the stitch can promote a local infection.
***A CVC should not be removed if symptoms are mild and it is possible that the CVC is not the source of these symptoms. An infected tunneled CVC can often be treated without removal, but this requires resolution of your fever and negative blood cultures while being treated with antibiotics. If you have a PICC that becomes infected, it will usually need to be removed to treat the infection. For implanted catheters, the specific location of the infection (bloodstream versus the pocket containing the port) will determine whether the catheter will need to be removed. If you have a high fever or are very ill, your doctor may decide to remove your CVC, even before blood cultures are completely processed, as CVC removal is one way to treat an infected CVC. Certain types of infection (for example, fungal) are extremely difficult to clear and typically require catheter removal. ¶

Thanks to the Centers for Disease Control and Oley Trustees, Darlene Kelly, MD, PhD; and Douglas Seidner, MD, for their assistance with this article.
Thank You for Your Support in 2011!
The following list represents everyone who generously contributed toward Oley's efforts in 2011. We also want to thank all of those who are not listed but have contributed in other ways.

**Ambassadors ($2,000+)**
- Geoffrey O. Burney
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- Darlene Kelly, MD, PhD
- Robin Lang Realized Planned Gift

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- Steve & Edithine Swensen

**Contributor News**

**Donor Profile**

**Dr. Jane Balint**

“I have had the privilege of taking care of children (and now adults, as my patients have grown up) with serious intestinal problems since I was a nurse at Albany Medical Center and took care of two of Dr. Howard’s PN-dependent patients. Now, as a pediatric gastroenterologist, I have a practice focused on those with intestinal failure. It was through Dr. Howard, my father (Dr. John Balint), and the family of one of those first patients that I learned of Oley and the tremendous support and education it provides to both consumers and clinicians. Oley is a unique resource in advancing the care of those in need of enteral and parenteral nutrition support.”

**Dr. John Balint**

“I’ve been in Albany for forty-nine years. Doing GI, I had a fair number of patients who’ve done incredibly well with TPN. I was fortunate to know Dr. Jim Halstead, who knew a great deal about nutrition. He said to me, ‘Would you like to have a division of nutrition attached to the division of GI?’ And that’s how we got Lyn Howard here. The relief of having somebody like Lyn arrive—it meant that I didn’t have to struggle with the parenteral nutrition aspect of my patients’ care.

“I was in at the start of all this [founding of the Oley Foundation]. Lyn and I flew out to San Francisco to pick up a check, which got Oley started. I think what the Oley Foundation does is wonderful, which is why I give you some money from time to time. It’s been wonderful having the Foundation around.”
listed below, yet have supported Oley by volunteering their time and talents. Please see additional tribute and memorial gifts, pages 14–15.

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Notable Gifts from Individuals
Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, the complete list of contributions received in 2011 begins on page 12. Between November 12, 2011, and January 18, 2012, gifts were received:

In Memory of
All those we lost this year, especially Matt & Angie; Alma Louise Anderson; Nancy Backinger; Katherine Bagby; Carolyn Burroughs; John Carter; Evelyn Joan Coll; Joyce R. Dancisin; Jim Davis; Ann DeBari; William Demrick; Jeff Dorin; Donald Engle; Woodrow & Roslyn Freee; Patrick Glantos; Richard M. Harris; Arthur & Marjorie Harshbarger; Robert M. Hoffman; Joyce Hydroron; Angelo Di Monte; Scotta Weymouth Karff; Dorothy Kelly; Robin Lang; Lisa Miller; Kyle Noble; Clarence “Oley” Oldenburg; Kay Oldenburg’s kittens; Carol Peirce; Fran Perini; Willis “Dick” Schultz; Ken Thiele; Matt VanBruun; Andrew Van Kleunen; and Bunny Wong

In Honor of
Mariah Abercrombie, 26 years on HPN; Mandy Allen’s birthday and 5 years on HPEN; the amazing support system the Oley Foundation provides; Julie Andolina; Jameson Atkinson, 10 years on TPN & lovin’ life; Sarah Ballak; Bettamarie’s family & friends; Bertha’s birthday & 10 years on HPN; Colorado State Infusion; Mary Ellen Costa’s courage; Frances Culp, 6 years on HPEN; Roslyn Scheib Dahl; Andrew Dean; Jackson Dietel; education & support for HPN patients & their families; Teresa Grasso, who was recently placed on TPN; the Jones family; Dr. Kishore Iyer; Dr. Darlene Kelly; the Kulig family; Sean May’s 13th birthday; David McGee; Kathleen McInnes; Michael Medwar; Rachel Miller & her family; the Oley Equipment-Supply Exchange program; the Oley Foundation; Oley Regional Coordinators; Ryan Peot, 16 years on TPN; Ellen Pierce’s, MD, 20 years on TPN; Aidan Raffe 6 years on G-tube; Alan Robinson; the Rosado family; J.T. Shearrow; Lia Smollen—20 years on HEN; Tammie & Rob Stillion; Greg Tongol, 21+ years on TPN; the United Ostomy Associations of America; Bobbiejo Wintoff’s multivisceral transplant in 2005; Don & Mark Young; and Kim Zeller

Matching Gifts
Jones Lang LaSalle; GE Foundation
We appreciate all gifts and kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. Thank you!
Above and Beyond

We are especially thankful for the generous planned gift realized this year from long-time Oley volunteer Robin Lang. Robin was a founding member of the Horizon Society and believed strongly in the society’s mission to ensure continuing support for HPEN consumers and their families.

Discover the many ways you can make a lasting difference to the Oley Foundation online at www.oley.org/bequest.html or by calling Joan Bishop or Roslyn Dahl at (800) 776-OLEY.

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In Memory of Robert Hoffman
Sharon Alger-Mayer, MD
Catherine Alvaro
Mary & Frank Aquino
Sandra Battaglia
Patricia & John Betterly
Joan Bishop
Nora Busold
Mr. & Mrs. Jay D. Campbell Jr.
Cathedral Academy Class of ’56 Pizza Group
Ciampino & Co. staff
Elizabeth Chiffolo
Joan Clough
Colonial Plumbing and Heating Supply, Inc.

NYS Workers’ Compensation Bd.
Susan Patterson
Tatyana Primero
Robert Redmond, Esq
Mr. & Mrs. Max Rodriguez
Michelle Schultz
Steve & Dee Ann Squadere
Thomas & Barbara Squadere
Dr. & Mrs. Robert Steiner
The Tuesday Breakfast Club
John & Carole Wheeler
Ann Winer
Edward Woltmann & Lori Riley

Contributor News

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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- B. Braun Medical
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Thank You!

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Thank You!
Good Luck Katie!

The Oley Foundation regretfully accepted Katie Swensen’s resignation this winter. For the last few years, Katie helped raise clinician awareness of Oley programs by coordinating our exhibits at non-Oley conferences. Before that, Katie directed the Regional Coordinator volunteer program.

We wish her luck in finishing her graduate degree, and in caring for Dominic. Thank you, Katie, for your many contributions!