IHPs, 504 Plans, and IEPs: What’s the Difference?

Donna Noble

Our thanks to Donna Noble for compiling the information below about the different tools available to help homePEN children overcome some of the obstacles they may face in obtaining an education. Donna is a patient advocate for ThriveRx, as well as a special education teacher and HPEN-consumer caregiver. Thanks, too, to Mary Patnode, an Oley board member, retired school psychologist, and HPEN consumer, for reviewing the article and for her input.

Additional information about these programs can be found at the Web sites listed at the end of the article.

Children on home nutritional support often have special medical needs that require attention during the time they would be at school. Or they may miss school for extended periods of time due to illness. Many of these children do not require and are not eligible for special education, but do require some special consideration or accommodations from their school systems due to medical needs. So the question becomes, how can these children successfully obtain an education but still have their special medical needs met?

There are several tools available to help make this possible. The three major supports are the Individual Health Plan (IHP), the 504 Plan, and the Individualized Education Plan (IEP). For children on home parenteral and/or enteral nutrition (HPEN), one or all of these plans might be useful.

**What is an IHP?**

An IHP is a plan that considers how to deal with what might happen with a student medically while the student is in school. It is designed to address medical issues that do not impact the student’s learning. An IHP is a formal agreement that outlines the student’s needs and a plan for addressing those needs. Parents or caregivers, the student, the student’s health care provider, and a

Consumers Invited to Major Meeting in Vegas

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) invites you to what promises to be an incredible research workshop, “Intestinal Failure: Latest Advances in Diagnosis and Treatment Including Transplantation,” February 7–8, 2010, in Las Vegas. Don’t miss this outstanding opportunity to learn from experts from around the globe about surgical options for SBS, motility disorders, quality of life, bacterial overgrowth, transitioning from PN to tube feedings, the role of growth hormone, tissue engineering, organ transplantation, and more.

Oley also invites you to extend your stay, and help at the Oley booth, February 9–11, at Clinical Nutrition Week, A.S.P.E.N.’s annual meeting that follows the workshop. “Booth duty” allows you to see the
IHPs, from pg. 1

A multidisciplinary team of school staff work together to develop the IHP. An IHP serves both the student and the school. It gives the student and his or her family the opportunity to discuss their concerns with school staff, and helps establish student, family, and school roles and responsibilities. It clarifies important things like how medication will be administered, how the student’s health status will be monitored, the location where care will be provided, and who will be providing the care. It should provide for staff training and specify who will provide that training. It can serve as the basis for ongoing teamwork, both between the family and school staff and among staff members. It also provides the school with an accurate, centralized source of information about the student’s medical needs, and with direction and authorization should a health need arise suddenly. To be sure the plan remains current, review dates should be written into the plan.

The IHP format varies from state to state and often from district to district. Unlike an IEP or 504 Plan, which has a standardized format, IHPs are developed by the school district. Certain health organizations, such as the American Diabetes Association, have also created boilerplate IHPs. No state or federal protection comes with an IHP. An IHP can be used alone or in conjunction with a 504 Plan (see sample IHP on page 8).

If your child’s circumstances change or you are not satisfied with the staff response, you can always request a meeting with the school. As an IHP is an agreement and not a legally binding document, there is no legal recourse if the district does not comply with the document.

Does my child need an IHP?

If your child has a health impairment or physical disability, he or she should have an IHP. It documents his or her needs and the services to be provided to that child. Remember: Even if your child is not receiving medication or infusing during school, it is important to have an IHP in place so the staff knows how to deal with any emergencies related to the feeding tube or venous access device. For the health and safety of your child, staff need to be prepared to deal with a tube/line emergency. I strongly urge parents to add an IHP to their child’s 504 Plan or IEP. The medical care component of the student is not addressed in the 504 Plan or IEP.

How do I develop an IHP?

The first step is to speak with your child’s health care provider(s). Discuss the school environment and together try to outline the health issues that might need to be addressed while your child is at school. This should include things you plan on, such as your child receiving medication, and things you don’t plan on, like an enteral tube getting caught on a doorknob and coming out. Ask your child’s health care provider(s) to document your child’s health needs and what he or she feels your child requires for support. Then speak with the school about developing an IHP. Bring all of the documentation with you when you meet with school staff.

As you think about whether your child would benefit from an IHP, or the 504 Plan or IEP discussed below, remember that parents are supposed to be a key component in the development of all these tools. You should make sure you are included in all steps of the process. As a parent you can have much power in advocating for your child. Usually the most effective way to use this power is to approach the school district in a collaborative and cooperative manner.

What is a 504 Plan?

A 504 Plan is a legally binding agreement between the parent(s) and the school district. It is a part of the Americans with Disabilities Act (ADA). Children who have disabilities that do not interfere with their ability to progress in general education are not eligible for special education services, but they may be entitled to the protection provided by a 504 Accommodation Plan. 504 Plans are used widely and for diverse needs. They can cover a single issue or several concerns.

504 Plans typically address accommodations in academic areas, but they can also be applied to nonacademic areas (such as band) and extra-curricular activities, to allow the student to have the whole school experience. The 504 Plan can follow the student to college and is also applicable in the workplace.

504 Plans are not as involved as, and do not cover all of the things covered in, IEPs (see page 7). A 504 Plan should provide for staff training and specify who will provide that training. The plan should also include review dates. A 504 Plan can be requested by the family or school personnel. It is developed by the
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.

Calming Rashes

My son has had multiple and severe G-tube site rashes stem-
ming from leakage. Calmoseptine® Ointment (www.calmosep-
tineointment.com), Critic-Aid Clear®, and Critic-Aid Skin
Paste® (www.us.coloplast.com) have helped immensely.

I have also had success with Medihoney®, a natural antibiotic
wound gel. It’s made from *Leptospermum* (manuka) honey, which
has antibiotic properties. If you get it in a tube, you can use it
on the skin around the G-tube site, then place gauze over it.
It comes in many types of dressings as well. More info about
Medihoney® can be found at www.medihoney.com or www.
dermasciences.com (the U.S. distributor).

I was first turned on to Medihoney® by another Oley forum
user. She and I know one another online outside of the Oley
network. She lives in Vienna, and apparently Medihoney® is
much more widely used in that area and throughout Europe.
Derma Sciences in New Jersey is the first to distribute Medi-
honey® in the United States.

I would have loved these suggestions when we first began our
tube drama. I hope they can be of help to others.

—Stephanie S.
Geneva, FL
stephsnfrd@gmail.com

Equipment-Supply Exchange

We’ve got news! Oley members Tammi and Robert Stillion have
volunteered to coordinate this important service. The Equipment-
Supply Exchange is a busy and popular program, and we are so
grateful to the Stillions for taking this on!

When you call to donate or ask about equipment, supplies, or
formula, you’ll talk to Tammi or Rob. Please let them know how
much you appreciate their efforts, and make their job a little easier
with a follow-up call to let them know
how you made out with any referrals.

Contact the Stillions with donations, requests, or questions at (866) 454-7351
or oleyequipment@aol.com. As always,
a full list of items available is posted
online at www.oley.org.
Regional Coordinator Program Grows by Leaps and Bounds

The Program
Regional Coordinators (RCs) are an integral part of the Oley Foundation’s outreach efforts. They provide peer support for HPEN patients and family members in a variety of ways. Some RCs coordinate local support groups, others are active on the Oley forum or answering phone calls, and others find different ways to reach out. If you need to speak to someone or are interested in a get-together, contact the volunteer nearest you. You are welcome to contact any of the RCs with questions or to talk, as they have an assortment of knowledge and experience to share. The complete RC list can be found at www.oley.org/volunteers.html.

If you are interested in becoming an RC, please call (800) 776-OLEY or e-mail Joan Bishop at Bishopj@mail.amc.edu.

New Program Director
We are pleased to announce that in September, Felice Austin, RC from Henderson, Nevada, assumed responsibilities as Oley Regional Coordinator Program Director. Felice brings a wealth of experience to this position. She has attended numerous Oley conferences, served as an RC for over fifteen years, and staffed the Oley exhibit booth at many meetings. Further, she has a degree in social work, and her daughter, Mariah, has been sustained on home parenteral and/or enteral nutrition (HPEN) for over twenty-two years—an experience that has presented Felice with many learning opportunities.

We are excited to see Felice combining her skills and experience with the enthusiasm of the Oley RC community, and look forward to working with Felice and all of the RCs to make Oley a household name in the homePEN arena.

New RC Volunteers
We have eight new RCs to introduce this fall! Let us tell you a little about each of them. (More detailed biographies can be found online at www.oley.org/Regional_Coordinators.)

Jameson Atkinson
Jameson Atkinson, of Watkinsville, Georgia, has been on HPN since 2001 due to short bowel syndrome. Since that time he has earned his bachelor’s and master’s degrees in preparation for a career in education. He is currently on HPN seven nights a week. Jameson knows how difficult it can be for young adults and teenagers who suddenly find themselves on IV therapy. Jameson strives to live life to the fullest, doing things such as scuba diving, skydiving, road trips, and socializing. Jameson can be reached at jameson84@charter.net or (706) 340-7261.

Brenda Dunn
Brenda Dunn joins us from Matamata, New Zealand. Brenda and Jodee Reid (see below) are helping Oley bridge continents. To this end, Oley has also formally partnered with the newly established PN-DU (for “parenteral nutrition down under”) support group. Brenda has been on HPN for ten years. Prior to that she was on enteral feeds with a PEG tube.

Brenda writes that her “first year on PN was lonely,” until she found the U.S. Yahoo TPN support group and Oley. Now she has started a “down under” support forum and writes that she is in the process of starting a Web site that “will complement others well set up around the world, but deal with our local and cultural needs.” Brenda can be reached at dunnb@no8wireless.co.nz.

Melissa Fedell
Melissa Fedell, of central Connecticut, was diagnosed with idiopathic gastroparesis in 2003. She has been on HPEN for over two years. Melissa runs IV hydration twelve hours every day and HPN twelve hours every night, anti-nausea medication around the clock, and EN feeds a few hours every evening, in hopes of one day being able to come off HPN. She has experience with PICC lines, different HPEN infusion pumps, and a gastric stimulator, and is preparing to have an intrathecal pain medication delivery pump surgically implanted.

Melissa writes, “I am very fortunate to be able to continue to work and maintain my career in the medical field. I have both my bachelor’s and master’s degrees. I am very proud of having accomplished this despite the obstacles I have faced. My becoming an RC is very important to me. I really would like to give back to a community that has helped me tremendously over the past two plus years.” Melissa can be reached at laprn4kids@att.net or (860) 436-6628.

Joanne Platt
Joanne Platt, of Howell, New Jersey, has been married for thirty-six years and has two adult sons. She is an RN, but is presently disabled. Joanne underwent a subtotal gastrectomy for an abdominal tumor in 1995. Along with numerous other complications, she developed gastroparesis. Her diagnoses also include malabsorption, dysmotility,
GERD, pernicious anemia, iron deficient anemia, osteopenia, gastritis, and depression, “to name a few,” she adds.

“I struggled for ten years,” Joanne writes, “depending on oral nutrition, motility meds, and little amounts of food. I became very malnourished, which led to severe neurological symptoms. In 2006, I went on HPN via a PICC line. I had amazing results, but developed too many infections, and went through five lines in one year. I went to my first Oley conference in June 2006. I learned so much that by August, I had a jejunostomy button inserted by a physician I learned of at Oley. I am now living the best quality of life in fourteen years.” Joanne can be reached at joanneplatt2006@aol.com or (732) 367-6735.

Jodee Reid, currently of Gibsonia, Pennsylvania, but originally from New Zealand, is mother to eight-year-old Matisse, who has been HPN dependent since birth due to chronic idiopathic intestinal pseudo-obstruction. She has three other children, ranging from eighteen to five years old. Matisse spent six years on HPN in New Zealand before they moved to Pittsburgh to wait for a multivisceral transplant. “Along with Brenda Dunn, a fellow Kiwi,” Jodee writes, “I aim to bridge the gap between HPNers in the United States and those down under in New Zealand and Australia. Brenda and I will work together to ensure more New Zealanders and Australians have access to the information and support provided by Oley.”

Jodee is very excited to be part of the international support Oley offers and hopes to hear from some fellow Kiwis and Ozzies (as well as North Americans) soon. Jodee can be reached at jodee1@zoominternet.net or (914) 417-5163.

Sanford Schimel, of Bronx, New York, was diagnosed with gastroparesis in 2004 and had his first EN tube inserted in 2005. Prior to this, Sanford sang opera professionally in Chicago, and worked as a travel agent in Washington, D.C., and New York City. He moved to NYC in 1996 to produce a play he’d written, while continuing as a travel agent. In 2000, Sanford succumbed to addiction and went into long-term residential treatment. While in treatment he discovered that his HIV had become full-blown AIDS.

He is now a substance abuse counselor. Sanford writes, “I became a substance abuse counselor in order to give to others what had been given to me: recovery (over eight and a half years and counting).” His motto, he says, is “Curl up and die or stand up and fight.” Sanford has experience with J-G, J- and G-tubes, PICC lines, and central venous catheters. His diagnoses are gastroparesis, low motility, malabsorption, AIDS, peripheral neuropathy, autonomic neuropathy, iron deficient anemia, osteopenia, and osteoarthritis. Sanford can be reached at sschimel@hotmail.com or (917) 392-0589. He has the Oley toll-free line in December as well (888) 610-3008.

Tammi and Robert Stillion, of Wauseon, Ohio, are volunteering as a husband and wife team. Before we knew Rob and Tammi were going to join us as RCs — or take over as coordinators of the Equipment-Supply Exchange program (see page 3) — Rob wrote an article for us. You can get to know the Stillions better by reading Rob’s article on the cover of this newsletter. They can be reached at tammiss705@aol.com, outdoorsman8888@aol.com, or (419) 349-3907.

Linda Stroshine, of Toledo, Ohio, was diagnosed with post-surgical gastroparesis in 2001, after her vagus nerve was severed during a Nissen fundoplication. She has been on TPN three times but is currently receiving all nutrition through a J-tube. Linda worked at a hospital as a continuing medical education conference coordinator for twenty-five years before she retired on disability in 2006. Since retiring, Linda has had increased success maintaining weight and controlling nausea.

Linda has been attending a Toledo-area support group for EN consumers since 2007. Her first Oley conference was in 2009 and she credits the experience with giving her a renewed outlook on life. At first, Linda wondered why she got this condition but now she feels that she has an answer—to help others deal with tube feeding. Linda hopes their group will grow to support more Toledo-area homePEN consumers while spreading the word about Oley. Linda can be reached at lindamoonglow@buckeye-express.com or (419) 726-2833.
Nutrition and You

With this article, we are pleased to introduce a new column in the newsletter. “Nutrition and You,” written by one of several dietitians who have long been active with the Oley Foundation, will address issues related to food and beverages. Carol Ireton-Jones, PhD, RD, has written this first article, in which she introduces the team of dietitians who will be writing this column, and also addresses some of the issues consumers might face in the upcoming holiday season.

Surviving Holiday Food Functions
Carol Ireton-Jones, PhD, RD

For many years, food and “nutrition” were less visible components of home parenteral and enteral nutrition (HPEN), with the technical aspects (tubing, pumps, technique) in the forefront. Now we know that what a consumer eats and/or drinks — even if they absorb very little — is extremely important. Laura Matarese, PhD, RD, LDN, FADA, CNSD, Cheryl Thompson, PhD, RD, CNSD, Marion Winkler, PhD, RD, CNSC, and I are excited to be starting this new column.

We are all dietitians. Laura is the Director of Nutrition at the University of Pittsburgh Medical Center’s Intestinal Rehabilitation and Transplant Center. Cheryl is a consultant who develops online medical education such as the Oley MY HPN modules. Marion, who is at Rhode Island Hospital, works with nutrition support patients in the hospital and at home. Laura, Cheryl, and Marion are all on the Oley Foundation Board of Trustees. I am in private practice and also do consulting in nutrition support.

We are writing this column for you, the consumer. What information do you need or want about nutrition? Please e-mail your ideas to us at cireton-jones@foodtherapyrd.com, or send them to the Oley office, care of Lisa Metzger at metzgel@mail.amc.edu (or 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208).

Enjoying the Holidays

If food and eating are issues for you, how do you survive holiday get-togethers, which all seem to center on food? It takes effort to attend activities and develop a social network. In some ways, attending a gathering is like exercising: getting started can be the hardest part, and you may not feel the reward until after you are done.

Set a goal to strengthen your “social endurance” by taking gradual steps. Little by little increase the types of events you attend and length of time you stay. When you feel you don’t have the energy or desire to attend, remind yourself that your presence can be very meaningful to the host and friends and family. If you are well enough, try to go. Get started building your social endurance — it will pay off in countless ways.

“Party” is defined as a gathering of people who have been invited by a host for socializing, conversation, and recreation. The definition does not include eating. You don’t have to eat! Rick Davis, President of the Oley Board of Trustees, cannot swallow. But, as he says, he enjoys parties because he can talk the entire time, without having to wait until he finishes a bite. Another lesson from Rick is that he goes to the parties and events. Often he carries a beverage, without drinking it, just to “fit in.” This gesture helps him feel comfortable. It also helps family and friends who might feel uncomfortable when someone who can’t eat joins them.

Holiday parties are ideal for strengthening social endurance because the food served is often in the form of appetizers or a buffet. You may find it easier to take a small taste of your favorites without anyone commenting on the small portion size. It may take longer to feel comfortable at sit-down meals or dinner parties.

Always choose healthy foods that you can tolerate and remember to sip your beverage slowly. Pace yourself and do not overdo it. Remember your hosts and other guests are glad to see you! Enjoy!
parents and a team of school staff. The school team usually includes an administrator and a case manager. In many cases where the issues addressed in the 504 are related to the child’s medical conditions, the medical team is also included as an active participant.

**Does my child need a 504 Plan?**

If your child’s medical issues significantly limit one or more major life activities, including school, then he or she should have a 504 Plan. The goal of a 504 Plan is to level the playing field by providing accommodations and modifications that allow the student the same opportunities as their “typical” peers.

When you are considering whether your child needs a 504 Plan, it is a good idea to think about all the concerns created by his or her home nutrition needs. If you have several concerns then a 504 Plan might be helpful. Before the 504 Plan meeting, think of what your child might need while he or she is at school, and what accommodations your child might require to meet those needs. If a student needs to empty an ostomy bag, for example, he may need access to facilities not usually available to students. If your child will need to have medication administered during a test, she may require extra time for the test. If your child misses school due to medical appointments or illness related to home nutrition therapy, accommodations may be required so the days missed will not count against him.

**What is covered in the 504 Plan?**

A 504 Plan can include adaptive equipment or assistive technology devices; an aide; assistance with health-related needs; school transportation; or other related services and accommodations. Specialized instruction is not covered in a 504 Plan. For children on home nutrition therapy, a 504 Plan is important to ensure, for example, they have frequent bathroom breaks, a clean place to change an ostomy bag, access to education if they must be home for long periods of time, and accommodations for any other special needs that may arise.

**What is an IEP?**

IEPs are generally for students who have documented gaps in learning beyond what might be expected based upon the normal curve. An IEP is an individualized learning plan, developed by a team, to address these gaps. However, an IEP can also be used when the gap is anticipated, such as with a child who will have difficulty keeping up due to frequent illness and absences, or a child whose hearing impairment, orthopedic impairment, or emotional disturbance necessitates modifications and/or accommodations in the curriculum. It is a legally binding document based on the Individuals with Disabilities Education Act (IDEA). IDEA ensures services to children with disabilities throughout the nation.

The federal government lays out the rules for IEPs, and states implement these rules. States may interpret the federal mandates differently and therefore IEPs are not exactly the same across state lines. Eligibility

*Tools for Better Living*

ThriveRx, formerly NutriThrive, Has a New Name!

Still the same great company, just with a new name!

ThriveRx is focused on highly customized care for individuals requiring intravenous nutrition and tube feeding. The new name, ThriveRx, was chosen to better reflect our holistic approach to care, and to provide synergy with the parent company, BioRx.

“ThriveRx has been amazing...they always have up-to-date information from my doctor, coordinate my health insurance needs and contact me monthly to see how I'm doing, and within a couple days everything is on my doorstep; it's that simple.” Shellie W.

1-888-6-THRIVE (888-684-7483) or info@thrivexr.net
www.thrivexr.net

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for special education (and therefore an IEP) also varies slightly be-
tween states due to differences in interpretation of the federal law. It 
is important to keep this in mind if you are moving and looking at 
school districts.

IEPs give you backing and guarantee procedural safeguards, such as 
due process. IEPs also call for mandatory progress reports.

**Does my child need an IEP?**

If your child has a condition or disability that interferes with or 
impacts his or her ability to learn and makes it that he or she cannot 
succeed in school without modifications to the regular curriculum,
then he or she may qualify for an IEP. There are many specific disability 
categories covered by an IEP, such as cognitive disability or a hearing 
impairment. There is also a category for “other health impairment.”

**Does my child's home nutrition therapy need qualify him or her for an IEP?**

In order for a child to be eligible for an IEP as “other health 
impaired” (OHI), the child’s strength, vitality, or alertness must be 
substantially affected. Examples include medical conditions that 
cause a student to miss many days of school, or fatigue issues that 
cause a student to need half days or reduced assignments. You should 
talk to your child’s health care provider(s) about whether you should 
seek an IEP for your child.

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**Enteral Medical Management Plan**

This plan should be completed by the student's medical team and parents/guardian. It has been 
created with relevant school staff and copies should be kept in a place that is easily accessed by the 
school nurse, trained personnel, and other authorized personnel.

School Year: ___________ Student’s Name: ______________________________
Date of Birth: ___/___/___ Initiation of Nutrition Therapy: ___/___/___
Grade: _______ Homeroom Teacher: ___________________________

**Contact Information**

Mother/Guardian: __________________________
Address: __________________________
Phone: Home (___) ——— Work (___) ——— Cell (___) ———
Father/Guardian: __________________________
Address: __________________________
Phone: Home (___) ——— Work (___) ——— Cell (___) ———
Student’s Doctor/Health Care Provider: __________________________
Address: __________________________
Phone: (___) ——— Emergency Number: (___) ———
Other Emergency Contacts: __________________________
Name: __________________________
Relationship: __________________________
Phone: Home (___) ——— Work (___) ——— Cell (___) ———
Conditions under which parents wish to be contacted by the school __________________________

**Feeding Pump Information**

Type of Pump Used: __________________________
Rate of Infusion: __________________________
Duration of Infusion: __________________________ Start Time: __________________________ End Time: __________________________
Formula Infused: __________________________
Can student hook up infusion independently?  ❑ Yes  ❑ No
Exceptions: __________________________
Procedures for Hooking Up and Disconnecting: __________________________
Type and Size of Gastric Tube: __________________________
Amount of Water in Balloon: __________________________

**To see the rest go to: www.oley.org or call (800) 776-OLEY**
An IEP can provide for modifications to the curriculum and accommodations in instructional methods and materials, assignments and classroom assessments, and time demands and scheduling. An IEP will also allow for accommodations during state testing situations, such as frequent bathroom breaks, extended time, and small group setting. Remember: any accommodations provided in the classroom must be available for standardized testing.

An IEP is developed by an IEP team. The team should include parent(s), the student if appropriate, a special education teacher, a general education teacher, a special education administrator, and related service providers as needed. Parents are a vital part of the IEP process. You need to advocate for your child and if you are not happy with parts of the IEP, you do not need to sign the document until you all come to an agreement. Parents must approve the entire IEP, including methods, materials, frequency of services, and so on. Further, any changes to the IEP (or any of these tools) need to be approved by the parents.

An IEP also comes with procedural safeguards, federal funding, and mandatory progress reports.

What if I need more information or don't think my school district is meeting my child's needs?

Here are some great Web sites for general information on IEPs, 504 Plans, and “Other Health Impairments”:

- idea.ed.gov
- www.diabetes.org/advocacy-and-legalresources/discrimination/school/504plan.jsp
- www.nichcy.org/Disabilities/Specific/Pages/healthimpairment.aspx

If your child is in school and you do not feel his or her needs are being addressed, talk to your school administrator. If that does not yield the results you want, ask to speak to the district special education coordinator. If your child has an IEP, you are already guaranteed due process rights. Part of the IEP process includes providing parents with a book on the rights guaranteed by the IEP. In the handbook it will list the appropriate numbers to call at the state level. Another good source of information is your state department of education Web site.

A video that includes Donna’s presentation of this material at the 2009 Oley conference is available to borrow from the Oley Video/DVD Library. Call (800) 776-OLEY or visit www.oley.org for details.
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We made a trip to our family doctor. He told us, “I think it’s a hernia, but it’s in an unusual area. I want a surgeon to look at you.” So off to the surgeon’s we went, and a test was ordered. One day in February 2001, as we were sitting in the doctor’s office, the doctor came in and told us, “You have a mass in your abdomen wrapped around your intestine. We think it’s cancer and we need to get it out right away.” That day everything changed.

**Surgeries and Surprises**

Tammi’s first surgery was the day after Valentine’s Day. A family friend who is an emergency room doctor went to check on Tammi and came out to where my parents, Tammi’s sister, and I were waiting. He told us they had had to remove a large section of Tammi’s intestine, but that she should be able to function with what was left.

Two days later, however, she was rushed back into surgery with complications. After the surgery Tammi had only six inches of her small intestine and two-thirds of her large intestine left. We were told she would have to go on parenteral nutrition (PN). Again we were on a road that would change our lives forever. Even as a medic I had had no real involvement with patients on PN. So the education began.

Tammi was discharged three weeks later. Our bedroom, which was done in a northern woods theme, suddenly began to look like a hospital room. Dressing change kits, saline, PN tubing, and IV poles took the place of other items. We learned about dressing changes, home PN (HPN), and J-tubes. I quickly became more familiar with central venous catheters, PICC lines and ports than I ever thought I would.

We found out Tammi would never be able to work again, and we went to check on Tammi and came out to where my parents, Tammi’s sister, and I were waiting. He told us they had had to remove a large section of Tammi’s intestine, but that she should be able to function with what was left.

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Tammi was discharged three weeks later. Our bedroom, which was done in a northern woods theme, suddenly began to look like a hospital room. Dressing change kits, saline, PN tubing, and IV poles took the place of other items. We learned about dressing changes, home PN (HPN), and J-tubes. I quickly became more familiar with central venous catheters, PICC lines and ports than I ever thought I would.

We found out Tammi would never be able to work again, and we started paperwork for disability. We were disappointed at how hard it was to get any help from the government—even after all those years of paying into the system. In addition to being a dad and a husband, I became a caretaker, and then, in some cases, an advocate. Meetings with attorneys and doctors took the place of the walks and bike rides Tammi and I had previously enjoyed.

After a few years of struggling financially, I took a second job to help meet our bills. As I found myself in a new battle with insurance companies, I began to learn about Medicare and insurance rules, and how to use them to our benefit. In the meantime, my mother did some research that indirectly led us to a home care company. They could answer my questions about billing and HPN and had a pharmacist on call to answer questions. Wow, I thought, what a great idea! Up until this point I hadn’t known these kinds of companies existed. It was the start of a wonderful relationship.

**Moving Forward**

Through all of this I found I had a beautiful wife. We became closer than ever and spent more time together doing things like watching movies on the couch, going for short walks together, and swinging on the glider on our deck. My wife had always loved to sew so I began to save up to get her things for sewing. During this time our sons graduated from high school. To pay for college, our oldest boy joined the U.S. Coast Guard; later his brother joined the U.S. Army.

Our routines revolved around IV poles, HPN bags, tubing, and catheter care. When planning trips, we considered how far Tammi could travel in a day and where rest stops were located. In 2007 came the news we had dreaded but expected: the son who was in the Army was going to Iraq. I worried this would have an adverse effect on my wife due to her medical conditions, but I soon found out she was the glue that held our family together. She put up a strong front for the family even though I knew she was worried sick. Our son regularly checked on his mom by e-mail and instant messaging and returned safely fifteen months later.

Our vacations became trips to different medical conferences. Through them, we learned about Oley. We attended our first Oley conference a few years ago and learned there were other people just like us.

**An Advocate’s Role**

In time I have come to understand that as a caretaker I have a large responsibility. I have learned that I have to be the advocate, insurance expert, and billing person, as well as spouse and parent. There is a patient bill of rights, and I’ve learned that it’s very important to become familiar with it, because it is there for us. I have learned how to deal with insurance companies and Social Security. I’ve learned there are government agencies to help us, and we need to use them to our benefit.

When Tammi is hospitalized, I do not hesitate to meet with the patient representative to discuss how I want things done. I often feel I know more about Tammi’s care than the nurses, and in some cases, more than the doctors. I am never afraid to tell them to stop if they are doing something that may adversely affect Tammi’s care. I’ve learned I can say I am staying with my wife during a procedure, especially one that involves her central line. Remember, it is your catheter and you know how to take care of it.

HPN does not have to change your life. It requires some adapting, but you still can lead a normal life. Never hesitate to ask for help if you need it. There are national support groups like Oley, and local support groups, some organized by Oley Regional Coordinators [like the Toledo group; see page 5]. Use them—they can provide a wealth of information. Find other people in your area who have the same conditions and ask for advice. Tammi and I just had a young lady from Ohio call us and we have started talking to her on a regular basis about things that can help her. As advocates and caretakers we have a responsibility to help others.

**Our Niche**

Our oldest son is now an officer in the Coast Guard. Our middle son is in the Ohio Army National Guard and going to college. Our youngest child, our daughter, is in college studying to be an early childhood education teacher. We recently moved into a farmhouse where I made a sewing room just for my wife. She has started to quilt.
Oley News

What’s New at www.oley.org

Check out the latest additions to the Oley Web site:
- “New to Oley?” button posted at www.oley.org
- “Tube Feeding Tips” page posted at www.oley.org/tubetalks.html

Nutrition Week, from pg. 1

latest products on the market, as well as talk to clinicians about Oley programs and services.

As one Oley volunteer put it, “One of the first things you learn when you have to live with being tube fed is that the more you learn about your condition, the better you can cope with it. I have found that being a volunteer for Oley at events like CNW allows me to share what I have learned, answer the questions of the health care community, and learn what is new.”

Another consumer who attended the 2009 CNW writes, “Interacting with the clinicians allows them to see HPEN consumers in a new light.... Many mentioned it was helpful to hear of someone’s experiences after going home on HPEN. Others said that hearing of my experiences... gave new meaning to what they do every day at work.”

Contact Joan Bishop at (800) 776-6539 or bishopj@mail.amc.edu, to request more information, and/or to register for the program.

Ongoing Research Trials

Study Investigates Whether Teduglutide (GLP2) Can Reduce HPN Dependency

Patient enrollment is under way in a Phase 3 study to confirm previously reported data that demonstrated teduglutide was well tolerated and significantly reduced parenteral nutrition (PN) dependence in short bowel syndrome (SBS) patients. Teduglutide is a proprietary analog of human glucagon-like peptide 2 that stimulates the repair and regeneration of cells lining the intestine. This international, double-blind, placebo-controlled safety and efficacy study is known as STEPS (study of teduglutide in PN-dependent short bowel syndrome). STEPS will compare daily subcutaneous dosing of 0.05 mg/kg of teduglutide to placebo over a 24-week treatment period. After completing 24 weeks, patients will be offered the option to enter an open-label extension phase for up to an additional 24 months, in which patients previously treated with teduglutide or placebo will receive teduglutide.

For more information on STEPS, please contact NPS Pharmaceuticals, Inc. at www.npsp.com, (908) 450-5300, or email Eric Kim: ekim@npsp.com or Linda Simrell: lsimrell@npsp.com.

The research study listed above has been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee; however, the Oley Foundation strongly encourages anyone considering participating in medical research to discuss the issue with their managing physician before signing up.

Information on these studies is available by calling (800) 776-OLEY or visiting our Web site at www.oley.org. Clinicians interested in having their study listed should complete the form at www.oley.org or fax the same information to (518) 262-5528.

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From the Desk of Joan Bishop, Executive Director

As many of you know, this year marks my “twenty-fifth year of service” at Oley. Celebrating this landmark anniversary has been overwhelming. I’d like to acknowledge all Oley members for their continued support throughout my journey.

It is through you that I have a greater understanding of “living” on homePEN. Without your patience and guidance I would not be in a position to help anyone in our community. I continue to cherish my time with you and look forward to serving your needs for many years to come. It is a privilege and honor.

As you will notice, the Horizon Society has many new members (see right). Earlier in the year Oley President Rick Davis asked, “What better way to celebrate Joan’s twenty-fifth anniversary than to give a gift that will help ensure the Oley Foundation’s future?” These donors have taken Rick’s suggestion to heart. I am deeply moved by each and every gift. Thank you! Oley holds a special place in my heart, and its future security is important to me. Beginning with the next issue of the newsletter, we plan to highlight some of the many ways you can make a planned gift to the foundation. It’s really very simple to do, and you can reap tax benefits, as well.

Hats off, too, to our Corporate Partners showcased in this issue. Coram and ThriveRx (formerly NutriThrive) continued to support us generously, financially and otherwise. InfuScience doubled their gift this year. How wonderful! And NPS Pharmaceuticals has joined us as our most recent partner. Please join us in welcoming them. I know you will enjoy reading more about each of these companies (see next page). Oley partners are awesome. We are privileged to have their support and to work with them to bring you ever better services. I cannot emphasize how important each financial gift—from Corporate Partners and individuals alike—is to our survival. Thank you!

Oley Horizon Society Blossoms!

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.

★ NEW! Felice Austin  
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Katherine Cotter
Jim Cowan
★ NEW! Rick Davis  
Ann & Paul DeBarbieri
★ NEW! David & Sheila DeKold  
Tom Diamantidis, PharmD
Selma Ehrenpreis
Herb & Joy Emich
★ NEW! Jerry Fickle  
Don Freeman
Linda Gold
Linda Gravenstein
The Grober Family
Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
★ NEW! Portia & Wallace Hutton  
★ NEW! Kishore Iyer, MD  
Darlene Kelly, MD
Family of Shirley Klein
★ NEW! Jim Lacy, RN, BSN, CRNI  
Robin Lang
Hubert Maiden
★ NEW! Laura Matarese, PhD, RD, CNSD  
Kathleen McInnes
★ NEW! Michael Medowar  
Meredith Nelson
Nancy Nicholson
Rodney & Paula Okamoto, RPh
Kay Oldenburg
Judy Peterson, MS, RN
Clemens Pietzner
Beverly Promisel
Abraham Rich
★ NEW! Gail Egan Sansivero, MS, ANP  
Roslyn & Eric Scheib Dahl
★ NEW! Susan & Jeffrey Schesnol
★ NEW! Doug Seidner, MD, FACP, CNSP  
Judi Smith
Steve Swensen
★ NEW! Cheryl Thompson, PhD, RD, CNSD,  
& Gregory A. Thompson MD, MSc  
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Rosaline Ann & William Wu
Corporate Partner Spotlight

**Coram Specialty Infusion Services**

Coram has been a proud supporter of the Oley Foundation for over twenty-five years, and is now in its thirtieth year of empowering home nutrition consumers through individualized customer service, clinical expertise, education, and support. Coram’s local nutrition support teams understand that every consumer is at a different stage of their treatment and their life, and take into account travel plans, work schedules, and nutrition needs in order to develop a therapeutic plan to enhance their quality of life.

Above and beyond locally available home nutrition support teams for each patient, Coram offers a broad array of in-home and online patient support, a patient advocacy hotline, consumer informational teleconferences, travel programs, and a quarterly support magazine. An in-depth resource for anyone in the parenteral or enteral nutrition community can be found at www.WeNourish.com — which features a consumer blog, extensive resource links, and a host of downloadable educational materials, as well as therapy-specific audio tutorials and educational videos.

**ThriveRx (formerly NutriThrive)**

The mission of ThriveRx (formerly NutriThrive) is to optimize the nutritional well-being of the homePEN consumer through advocacy, clinical care, and education. The company writes, “Advocacy is at the forefront of our agenda, as reflected in our customized products and services, advisory boards, and Consumer Advocate program. Our goal is to empower consumers and their families to live life!”

ThriveRx has put its mission into action as a Golden Medallion Partner, and contributes additional financial support to Oley through the company’s Full Circle program: $1 for every day of parenteral nutrition and $1 for every course of enteral nutrition that its patients require nationwide. ThriveRx is committed to giving back to improve life for those on homePEN.

**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.

**NPS Pharmaceuticals**

NPS Pharmaceuticals is developing new treatment options for patients with rare gastrointestinal and endocrine disorders. The company is currently conducting two Phase 3 clinical studies. Teduglutide, a proprietary analog of GLP-2, is being evaluated in a Phase 3 clinical study known as STEPS for parenteral nutrition dependence associated with short bowel syndrome and in preclinical development for gastrointestinal mucositis and other pediatric indications. NPSP558 (parathyroid hormone 1-84 [rDNA origin] injection) is being evaluated in a Phase 3 clinical study known as REPLACE as a hormone replacement therapy for hypoparathyroidism. For more information, please visit www.npsp.com.
Conference Coverage

Scenes from St. Petersburg — More at www.oley.org!
Individual Donors

The following list represents everyone who contributed between July 24 and September 30, 2009. 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.

**Ambassador ($2,000+)**
- Dianne Davis, Rick Davis
  - Hike-a-thon

**President’s Circle ($1,000–$1,999)**
- Frona Brown, in honor of Esther Ann Adler

**Benefactors ($500–$999)**
- Marion Hirscher, in honor of Patricia Brown, RN
- Kenneth Knapp, Rick Davis
  - Hike-a-thon
- Janet Platt
- Margaret “Marge” Taber

**Sponsors ($250–$499)**
- Larry Dean Evans, Rick Davis
  - Hike-a-thon
- Cheryl Thompson, PhD, RD, CNSD,* Rick Davis
  - Hike-a-thon

**Patrons ($100–$249)**
- Richard & Faith Dillon
- Janet M. Gatty, Rick Davis
- Stuart Gordon, in memory of Irmigails Gordon
- Eric Hill, in honor of Paul Armiger & Rick Davis
  - Hike-a-thon
- Janis Johnson, Rick Davis
  - Hike-a-thon
- Jesse Jones, Rick Davis
  - Hike-a-thon
- Marlene & Julian Sloter, Rick Davis
  - Hike-a-thon
- Chris White, Rick Davis
  - Hike-a-thon
- Rose** & Bill Wu

**Supporters ($50–$99)**
- Steven Atkinson, via United Way
- Mary Barron, Rick Davis
  - Hike-a-thon
- Mary Blackwell
- Lowel & Myrna Burningham, Rick Davis
  - Hike-a-thon
- Susan Carmichael, Rick Davis
  - Hike-a-thon
- Mary Friel
- Sheryl Jones, Rick Davis
  - Hike-a-thon
- Heather Kendall
- Janet Kennedy, Rick Davis
  - Hike-a-thon
- Carl & Mabel Little, Rick Davis
  - Hike-a-thon
- Eve Longing-Callahan, Rick Davis
  - Hike-a-thon
- Tiffany Matthews, RD
- Mary Bea May
- Mary Miller, in honor of my sister, Barbara Klingler, on HPN 23 years!
- Leslie Modena, in honor of the Vanderbilt Center for Home Nutrition

**Friends (Up to $30)**
- Mary & John Annese, Rick Davis
  - Hike-a-thon
- Mary & John Annese, Rick Davis
  - Hike-a-thon
- Thomas Estes, Rick Davis
  - Hike-a-thon
- Sheryl Longobardi, Rick Davis
  - Hike-a-thon
- Eli & Joan** Medwor, Rick Davis
  - Hike-a-thon
- Lois Moran
- Janet & Michael Reilly, Rick Davis
  - Hike-a-thon
- Mary Miller, in honor of my sister, Barbara Klingler, on HPN 23 years!
- Leslie Modena, in honor of the Vanderbilt Center for Home Nutrition

**In Memory of Ryan Evan Duffy**
- Lorraine Barabasz
- Donald Darmer
- Mr. & Mrs. Donald Nadler

* Oley Trustee
** Oley RC
*** Oley Staff

Choose Oley as Your United Way Charity

Although the Oley Foundation is not a United Way agency, we can be supported through United Way employee giving campaigns. Workplace giving can be a convenient, painless way to give a small amount from each paycheck. You can take advantage of this, and help us too, by designating the Oley Foundation on your United Way campaign pledge card. Questions? Contact Roslyn Dahl or Joan Bishop at (800) 776-OLEY, or dahlr@mail.amc.edu or bishopj@mail.amc.edu.

Oley Corporate Partners

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

**PLATINUM LEVEL PARTNERS ($70,000+)**
- Nutrishare, Inc.

**GOLDEN MEDALLION PARTNERS ($50,000–$69,999)**
- Coram Specialty Infusion Services
- ThriveRx (formerly NutriThrive)

**SILVER CIRCLE PARTNERS ($30,000–$49,999)**
- Nestlé HealthCare Nutrition

**BRONZE STAR PARTNERS ($20,000–$29,999)**
- Abbott Nutrition
- InfuScience, Inc.

**PATRON LEVEL PARTNERS ($5,000–$9,999)**
- Applied Medical Technology, Inc.
- Chemique Pharmaceuticals
- Critical Care Systems, Inc.
- EMD Serono, Inc.
- NPS Pharmaceuticals
- Walgreens-OptionCare

**BLUE RIBBON PARTNERS ($2,500–$4,999)**
- Baxter Healthcare
- B. Braun Medical
- Kimberly-Clark Sherwood Clinical

**CONTRIBUTORS ($1,000–$2,499)**
- C.R. Bard, Inc.
- Moog Medical Devices Group/Zevex

Choose Oley as Your United Way Charity

Although the Oley Foundation is not a United Way agency, we can be supported through United Way employee giving campaigns. Workplace giving can be a convenient, painless way to give a small amount from each paycheck. You can take advantage of this, and help us too, by designating the Oley Foundation on your United Way campaign pledge card. Questions? Contact Roslyn Dahl or Joan Bishop at (800) 776-OLEY, or dahlr@mail.amc.edu or bishopj@mail.amc.edu.
Chat with Others—Free!
If you haven’t taken advantage of Oley’s toll-free networking, try it now! Two telephone numbers are regularly staffed by experienced home parenteral and/or enteral (homePEN) consumers or caregivers. These volunteers are available to talk about day-to-day issues, ideas on coping, etc. Check www.oley.org or call the Oley office at (800) 776-6539 for a brief biography of these volunteers. As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

November 2009
Lou Pacilio, on HEN due to a swallowing disorder
Leeds, MA—EST (888) 610-3008
Robin Lang, on HPN since 1980 due to SBS/surgical error
Friendship, ME—EST (888) 650-3290

December 2009
Sanford Schimel, on HEN since 2005 due to gastroparesis
Bronx, NY—EST (888) 610-3008
Liz Tucker, on HPN since 1986 due to SBS/Crohn’s disease
Lakeville, MN—CST (888) 650-3290

We Have a Winner!
Congratulations to Kathleen McGinnis, the lucky winner of Oley’s $50 membership drive drawing. Be sure to enter the contest next year for your chance to win.

Join Us in Philadelphia
Oley and the Pennsylvania Chapter of the American Society for Parenteral and Enteral (PASPEN) have planned an exciting day to further your understanding of home nutrition support. Join us Wednesday, November 11, 2:00–7:00 p.m., to hear formal lectures and panel presentations on: optimizing communication between the patient and healthcare team; current and future practices in SBS and other malabsorptive states; updates on nutrition management strategies for IBD; and fluid and electrolytes management with diarrhea. The outstanding faculty will include Kristin Andolaro MS, RD, LDN; Bettemarie Bond; Charlene Compber, PhD, RD, FADA, CNSC, LDN; Maryann King, MPH, RD, CNSD, LDN; Doug Seidner, MD, FACG, CNSP; Marc Strantz, PharmD; and Don Young.

Enjoy the information and expertise, as well as networking with your peers, visiting exhibits, and light refreshments. Fees: Oley consumers, free; students, $30; PASPEN members & LaSalle staff, $40; and non-PASPEN clinicians, $55.

Consumers, to learn more or to reserve a seat, visit www.oley.org, call Oley at (800) 776-6539, or e-mail Joan Bishop at bishopj@mail.amc.edu. Clinicians, please contact Bethany Beckerdite at (732) 713-9805 or sunnyb77@yahoo.com.