ISSUE FOCUS:
Pediatric Nutritional Support
Managing Nutrition Therapy at School
The transition from providing tube-feeding and parenteral nutrition at home to providing this support at school requires a certain amount of adjustment. This article highlights how, with planning and organization, you can help make the adjustment easier.

The Essential Components of Success in Improving Oral Intake: Tactics Parents and Caregivers Can Try At Home
For some children who are dependent upon tube feeding or parenteral (IV) nutrition for their primary nutrition, the transition to oral feeding can be a challenge. Learn tips and strategies that can help make this transition go smoothly.

In Good Hands: Preparing Your Child for a Medical Procedure
No parents want to hear their child’s physician suggest the need for a medical procedure, no matter how straightforward. Learn what healthcare providers — and you — can do to help your child cope with having a medical procedure.

Emily Koprucki: Life Lessons from a Teenager on Nutrition Support
Emily Koprucki is a bright, funny 16 year old — who happens to be on nutrition support. Read her story and learn how she and her family faced a difficult health situation with strength and optimism.

2012 Small Steps to Big Steps Consumer Teleconference Series
Join us for our free consumer teleconference series — a great way to learn about topics that affect nutrition consumers from the comfort of your own home.

Pediatric Intestinal Failure-associated Liver Disease: Causes, Prevention and Treatment
For children, one of the possible complications of parenteral nutrition is pediatric intestinal failure-associated liver disease (IFALD). Learn about how this condition can affect children and what can be done to prevent and treat it.

Giving Our Children Wings: A Journey of Independence for HPEN Families
All parents must face “letting go” at many stages of their child’s life — and this may be even harder for parents of children on HPEN. One of our consumer advocates relates how she learned the joys of letting her daughter spread her wings.
It is a great privilege to serve as guest editor for this issue of *Celebrate Life*, a magazine devoted to providing practical, important and timely information to home nutrition patients and their families. As an Assistant Professor of Pediatric Gastroenterology, Hepatology and Nutrition at David Geffen School of Medicine at University of California, Los Angeles, it gives me great pleasure to see this issue of *Celebrate Life* dedicated to pediatric nutritional support. Children on home parenteral and enteral nutrition are a unique and underrepresented group of patients. Their needs are challenging and complex, and are best met by multidisciplinary teams composed of pediatric gastroenterologists, surgeons, pharmacists, dietitians, occupational therapists, feeding specialists and social workers, all working hand-in-hand with patients and their families.

In this issue, Barbara Crouse, RD, CSP, CNSC, provides an overview on the importance of nutrition in maximizing growth and development during childhood, and emphasizes the significance of tracking growth and weight gain in a longitudinal fashion. Anne K. Brettschneider, RD and Karen Hamilton, MS, RD, LD, CNSC, provide parents with practical advice on managing pediatric nutrition therapy at school, with an emphasis on allowing children to achieve important milestones by permitting them to participate in everyday events with peers.

Beth Carter, MD, Assistant Professor of Pediatrics at Texas Children’s Liver Center and Baylor College of Medicine, and Mary Elizabeth Magness, MEd, Certified Child Life Specialist, shed light on how parents can best prepare children of various ages for medical procedures.

It is wonderful to see two articles in this issue written from the perspective of patients and their families. Valerie Hansen’s profile of Emily Koprucki, a long-term HPEN teenager who is excelling both inside and outside of the classroom while receiving nighttime TPN, is inspirational. Linda Gravenstein, the mother of a long-term HPEN child who is now 30 years old, discusses ways to best support a child and prepare him or her to lead a full and independent life. Both of these articles illustrate the importance of family in successful delivery of nutritional support.

Khimberly Schoenacker, RD, CSP, CD, offers useful advice to help parents work with their children to prevent oral aversion and maximize oral stimulation and intake. This is a particularly challenging issue for children who are dependent on parenteral nutrition from early in life. And finally, I offer an article on a related topic, which is the prevention and treatment of intestinal failure-associated liver disease, an entity that can be prevalent and troublesome for children on long-term home parenteral nutrition.

I am extremely pleased to contribute to this issue of *Celebrate Life*. I hope you enjoy these articles as much as I have, and want to emphasize that we would appreciate your thoughts and feedback.

Sincerely,

Robert S. Venick, MD
Assistant Professor of Pediatric Gastroenterology, Hepatology and Nutrition
David Geffen School of Medicine at University of California, Los Angeles
The Role of Nutrition in Optimizing Growth & Development

By Barbara Crouse, RD, CSP, CNSC
As healthcare providers and the general public agree, adequate nutrition is critical to optimizing childhood growth, including physical and mental development. Adequate nutrition combines with other factors — including patient-centered healthcare, appropriate stimulation, timely learning opportunities, positive reinforcement of new behaviors, and a loving and supportive home environment — to support a child’s growth and development to his or her full potential.

Measuring Up
Parents and caregivers, especially of infants and young children, are the most important members of the child’s healthcare team. As your child’s advocate, you can positively impact your child’s growth and development by:

- Insisting on measurement of weight and height (length for infants) at each physician/clinic visit and having these measurements plotted on a gender- and age-appropriate pediatric growth chart.
- Making sure that at each healthcare visit until your child is three years old, your child’s head circumference is measured, and this measurement is plotted on a head-circumference-for-age growth chart.
- Reviewing and discussing these charts, and your child’s progress, with your child’s healthcare team. (These charts are available for download at cdc.gov/growthcharts.)

Given the active nature of most children, obtaining accurate measurements, especially for length or height, can be a challenge. But by taking these measurements at each healthcare visit, any measurement errors will become apparent and your child’s true growth pattern will emerge.

Why is this measurement and tracking so important? Comparison of your child’s growth to that of his or her peers through the use of standardized pediatric growth charts is important in identifying and addressing growth failure. There are several definitions of “growth failure,” also known as failure to thrive (FTT). However, most clinicians believe that simply a drop in weight and height is a basic definition, as well as a reason to intervene nutritionally.

For example, a two-year-old boy who weighs 28 pounds falls in the 50th percentile on the weight-for-age growth chart. This means that he weighs more than 50% of all two-year-old boys. If this same boy, now 2½ years old (30 months), has lost one half-pound and weighs 27½ pounds, he is now at only the 25th percentile on the weight-for-age growth chart. Now he weighs more than only 25% of 2½-year-old boys. While a weight loss of only half a pound may seem small, in a young child this is a red flag for nutritional deficiency. When plotted on a growth chart, it’s quite evident that something is amiss, even though the child may not be underweight for his height.

Along these same lines, routine measurement of head circumference provides information on the rate of brain growth in the first three years of life. During this period, your child’s brain should nearly double in size. Poor nutrition not only stunts physical development, but also brain growth, and therefore mental development.
What You Can Do

You can help your healthcare team sort out the reason(s) for any weight or growth changes in your child and put a plan in place to promote more normal growth. Growth failure is often attributed to several medical and environmental factors; however, the most common reason for poor growth is inadequate intake of calories and nutrients per the individual needs of the child. For a child who requires parenteral nutrition (TPN) and/or tube feeding for a portion of their nutrition intake, it is critical to ensure that these specialized feeding methods are continually adapted to meet the child’s needs; this can be done through routine evaluation of the child’s physical growth.

At the same time, the goal for most such children is to minimize the need for nutrition support, as appropriate to the child’s medical situation. You can help your child succeed in this regard by promoting development of oral feeding skills, starting in infancy. With a young infant, this may be as simple as maintaining eye contact and smiling during nursing or bottle feeding. For an older child, it may involve engaging the child in family mealtimes and providing as much positive interaction during meals as possible. Providing verbal praise for trying new foods and encouraging self-feeding can also help. If your child lacks interest in food, you may need to begin with praise for when the child looks toward the food, and work gradually from there. This kind of oral feeding therapy beginning in infancy can make an enormous difference to your child’s development, including that of later feeding skills. For infants who are unable to take food via the gastrointestinal tract, please ask your healthcare team about non-food methods for teaching oral feeding skills. Request a referral to an oral feeding specialist if your child’s regular team is unable to fulfill this request.

Childhood is an exciting and rapidly changing period in every individual’s life and presents a unique opportunity for you to help your child achieve his or her full potential. Help your child seize this opportunity by working collaboratively with your child’s healthcare team.
Managing nutrition therapy for your child at school can provide you, your family and your child with increased flexibility in your schedule. Even more importantly, it can enable your child to achieve important social and psychological milestones by allowing him or her to participate in everyday events with peers.

Of course, the transition from providing tube-feeding and parenteral nutrition at home to providing this support at school requires a certain amount of adjustment. However, there are ways to help make that adjustment easier. A little planning and organization — to make sure you have provided ample education to school staff, to prepare your child for the task, and to ensure that your child has all the equipment and formula needed — are the keys to successfully managing tube feeding, parenteral nutrition, or both, at school. Using the three pillars of preparation — Planning, Education and Communication — you can set the stage for a safe, happy and rewarding educational experience for your child.

Planning

Much of your planning will take place well before the school year starts. To start, some key issues will need to be considered, and you’ll want to address them with school staff. Start by determining your points of contact at the school and scheduling a meeting with each of them. The goal of each meeting will be to discuss your child’s needs while in school, and to ensure that these needs will be met on a daily basis. In addition, you’ll need to obtain the proper paperwork from the school for nutrition therapy administration to be approved.
During the meetings, review the items and questions listed below. Keep in mind that you are the expert. You know your child and his or her disease state, and you have become skilled in providing your child’s nutrition support.

- **Prescription review.** Review your child’s nutrition support prescription, including the rate, the time it takes to administer, positioning, water flushes, oral feedings, potential scheduling conflicts at school, volume per day, medication list, and assistance needed to feed. Questions to ask include:
  » Who will be administering the feeds or overseeing the feeding?
  » Who will make adjustments when needed?
  » How much monitoring will occur and how will this be communicated to you?
  » Will adjustments be made for oral intake and tube feeding intake?
  » Will the current feeding schedule work at school, or do adjustments need to be made?
  » What are the school’s protocols for administering tube feedings or parenteral nutrition? Can you receive a copy for your medical team to review?
  » What type of documentation will you be provided regarding your child’s intake while at school?

- **Supply management.** Provide a list of the formula and supplies that your child will need throughout the day. These items may include feeding bags, syringes, tape, gauze, formula, a low-profile feeding device (button), tube, a feeding pump, backup batteries for the IV pump, and a pump troubleshooting guide. Questions to ask include:
  » What type of training/education does the school staff need to feel comfortable with providing your child’s nutrition therapy during school hours?
  » Where will your child’s supplies be stored and labeled?
  » When is the best time for daily supplies to be brought in?
  » Can you bring in a week’s worth of supplies at a time? Can it be stored at school?
  » If the formula needs to be mixed, should this be mixed at home or at school?
  » What is the back-up plan if the feeding pump breaks down at school?
  » Are school staff familiar with your child’s equipment and supplies, such as the feeding pump?
  » Does anyone need training on the equipment and supplies?
  » How should changes to the therapy regime, or issues that have been identified, be communicated to the nurse?
  » Who should the nurse contact with concerns?

During your meetings, you can also tell the school staff about other preparations you’ve made:

- **Emergency kit.** Prepare an emergency kit to keep at the school. For example, you can put together a plastic tote labeled with your child’s name and include extra syringes, extension sets, a feeding bag, a feeding tube,
a low-profile tube, formula, clamps, tape, and batteries for the IV pump. Work with your home care company to determine what supplies your insurance company will cover per month that can be stored at school.

- **Contact list.** Develop a contact list and provide that list to school administrators. The list should include:
  - The dietitian that oversees nutrition at your clinic.
  - Your child’s physician.
  - The dietitian from your supply company.
  - A secondary caregiver contact.
  - Yourself.

**Education**

Informing school staff about your child’s medical condition, as well as educating them about the specific condition and therapy needed, can help clear up misconceptions and reduce anxiety for you, your child and school personnel. For instance, sitting down with your child’s teachers and making sure they understand why a child is tube-fed and how tube feeding works can help. You and your child may also want to educate your child’s friends and classmates. Speaking to these children about nutrition therapy can help reduce any confusion and allow your child to feel more comfortable at school. It is best to talk to your child’s peers only if your child is comfortable enough to provide factual answers.

Your Nourish™ Nutrition Support Team can provide guidance on managing feeds at school. They can outline how your child should be tube-fed or IV-fed, as well as the feeding plan for when your child is attending school. Your child’s healthcare team can supply specialized presentations and educational materials to help explain the facts to the school. They may also be able to provide educational conferences to your child’s school personnel.

**Communication**

Open communication between you, your child, the school, and your home care and medical team is the best way to make the school year go as smoothly as possible. Regular communication between parents and school personnel ensures that both parties are kept informed of complications in therapy provision, as well as any behavioral changes or other warning signs from your child.

Develop a support network in the school that includes the school nurse, teacher, and administration, and be sure to check in regularly with them and your child about how the nutrition plan is working. Keep your healthcare team (physician and home care provider) advised if anything needs to change in your child’s tube-feeding or parenteral nutrition plan.

Keep in mind that once the final decision is made for your child to attend school and receive nutrition support, it will take some time for everyone to adjust, especially your child. This is a big change, and every child will react differently. To make the transition as smooth as possible, talk to your child about the positive effects that having nutrition therapy at school will have on his or her growth and development.

If you have questions about your child’s transition to nutrition support at school, be sure to call your Coram Consumer Advocate or local branch for assistance. Coram can help provide the support you need during this very important time in your child’s life.
The Essential Components of Success in Improving Oral Intake: Tactics Parents and Caregivers Can Try at Home

By Khimberly Schoenacker, RD, CSP, CD
If only eating were simple and completely instinctual, then possibly every human being would enjoy it and many feeding problems would not exist. However, eating is only instinctive for the first month of life. After the fifth month of life, primitive reflexes drop out and eating becomes solely a learned behavior.¹

Whether your child has struggled medically, or is thought to have a “behavioral” problem that has resulted in poor intake — or even both — you can still teach your child to eat. This is especially important if a child is dependent upon tube feeding or parenteral (IV) nutrition for their primary nutrition. While a child’s nutrition needs are being met through nutrition support, one might assume that there is no need to teach the child to take food orally. In fact, this teaching becomes even more important because of the need to ensure that the child becomes comfortable with oral stimulation and enjoys food and the eating experience. The hope is that at some point, the child may be able to rely more heavily on an oral diet and less on nutrition support.

By creating a peaceful, fun and supportive atmosphere during meal or snack time, you can help your child enjoy the tastes, smells, and touch/feel of food and make positive associations with food. Before you try any of the techniques in this article, however, first refer to a speech pathologist, occupational therapist or pediatrician for guidance and safety. These clinicians will be able to determine if your child can safely eat or drink. They can also help you decide what foods to choose and how to recognize important milestones that are key to healthy eating.

The Feeding Hierarchy

To start, it helps to understand a bit about the process of learning to eat. There are several steps to what is called the feeding hierarchy — the complex process by which a child learns to accept food and eating. These steps are:

1. Tolerating being near food
2. Interacting with food
3. Smelling food
4. Touching food
5. Tasting food
6. Eating food

“When I first came to work for a children’s hospital, I observed a mother reluctant to have a feeding tube placed in her daughter. Despite the fact that her child could not eat or maintain her weight, let alone thrive, this mother remained resistant. It wasn’t until I had a heart-to-heart conversation with my own mother that I began to understand. Every parent wants their child to eat a “normal” diet and grow up to be a strong, healthy individual. I grew up with a sister who had cerebral palsy and eventually became dependant on a feeding tube. My mother described her feelings of failure as a mother and her painful disappointment that her daughter could not eat “like a normal child.” My mother’s story helped me better understand why this mother was reluctant to accept her child’s feeding challenges, as are so many other families that I have encountered during my career.

If your child is having issues with feeding orally, know that you are not alone. Also know that there is much you can do to help your child progress to the ultimate goal of eating. I hope this article helps you during this period of challenge and growth.”

– Khimberly Schoenacker
All children need to go through each of these steps, and your child may be anywhere along this “ladder.” Wherever your child is in the hierarchy, this article can help you move your child forward and progress up the ladder towards eating.

Transitioning from Nutrition Support to Eating by Mouth: A Parent’s Checklist

For those infants and children who require nutrition support, it is critical to prevent oral aversion — when a child avoids eating — to help ensure that the eventual transition to eating by mouth is successful. Below are some things to consider before this transition is suggested:

- Is the original rationale for TPN or tube placement resolving?
- Is the child medically stable (are there any upcoming surgeries, anticipated illnesses due to weather changes, etc.)?
- Does the child have stable gains in weight and height?
- Considering family stability and the level of stress in the home, is this the right time to make changes?
- Are you able to focus on structured meals?
- Is your source of food secure? For instance, if the formula is paid for through insurance, can your family afford food or an oral nutrition supplement?

Even if a child remains 100% dependant on TPN or tube feeding, a parent can still begin to prepare their child to learn to eat by mimicking a normal eating pattern as much as possible. For infants, 7–8 feeds per day, spaced 3 hours apart, is typical; for toddlers, 3 meals and 2–3 snacks every day is ideal. Feeding while sleeping or lying on their back is not the most normal way to eat, but necessary for some. If your child is able, have him or her sit in a highchair or be in a breastfeeding position during feeds to help promote the sensation of eating. One important goal is for them to associate being full with food, not with the feeding pump.

Making Eating Enjoyable

Once you are ready to move your child to eating by mouth, your goal is to make eating a positive experience. If a child associates pain or discomfort — such as from reflux or vomiting — with eating, this negative experience can teach him or her that eating is not fun. However, as a parent, you can help your child learn that eating can be pleasant. Make eating fun by using positive reinforcement, such as praising, cheering, clapping and positive comments. Don’t be afraid to get silly with your child. High expectations and forcing your child to eat will put a lot of pressure on your child and could make him or her want to avoid eating. If your child is having problems, simply refer back to the feeding hierarchy to see where he or she is at that moment, be patient, and remember to praise every small step of the way.

Try the following tips to help your child learn to appreciate food and enjoy mealtime:

- Stimulate your child’s senses of smell, touch and taste.
  - Bring the child into the room where food is cooking.
  - Bring the food near the child’s nose.
  - Model leaning down and exaggerating smelling: “Mmmmmm…. ahhhh.”
  - Play with the food — build, paint, make animal teeth (think walrus), balance it on your nose — whatever you prefer. Make food fun!
• Make food accessible to small hands, mouths and tummies.
  » Present the food in small, easily chewable bites or in long, thin strips that the child can easily hold.
  » Present only 2–3 foods on a child’s plate at a time, with one being a food your child prefers.
  » Remember, children have small bellies and each food item should be approximately 1 tablespoon per year of age.

• Encourage your child to tolerate more and different types of food.
  » Describe the properties of the food while it is in front of your child. For instance, talk about taste, smell, color, texture, sound and temperature.
  » Manipulate food near your child in a creative or educational way. The child will watch food preparation because it is interesting.
  » Place food on a napkin or table next to your child and subtly move it closer to him/her as tolerated.

• Make your meal and snack times structured and consistent.
  » Adopt a routine for all components of the meal, including preparation, serving food, mealtime and clean-up.
  » Consider having a “warm-up routine” before eating to let your child know food is coming. For instance, try washing your hands or setting the table. Or tickle the muscles around a baby’s to “wake up” the child and make him or her more aware.
  » Limit snack time to 15 minutes, and meals to no longer than 30 minutes.
  » Always end the snack or meal in a pleasant manner.

• If your child is old enough, get him or her involved in food and mealtimes.
  » Have your child serve him- or herself with a utensil.
  » Have your child help with food preparation using utensils.
  » Have the child help with peeling, cutting and stirring.
  » Have your child pass a food container to another person.

Mealtime Dos and Don’ts

DO:
• Support independence — encourage your child to feed him- or herself.
• Allow a child to express preferences by providing a choice of two items.
• Create a schedule and routines.
• Establish a comfortable environment for eating.
• Eat with your child and be a good “eating role model.”
• Use safe positioning to avoid opportunities for choking or falling. Have your child sit upright when eating, without slouching.
• Offer easy-to-eat foods.
• Provide a positive environment.
• Have fun and allow your child to get messy.
• Practice patience.
• Use positive “can-do” language such as “try it” or “just one bite.”

DON’T:
• Don’t allow daylong grazing.
• Don’t offer giant portions.
• Don’t force food.
• Don’t use distractions.
• Don’t offer bribes, pressure, delayed rewards or punishments.

Continued on page 29
In Good Hands:
Preparing Your Child for a Medical Procedure

No parents want to hear their child’s physician suggest the need for a medical procedure, no matter how straightforward. Hospital? Needles? Operation? Thoughts and fears can start to swirl in your mind. And that’s where the calm, professional approach of the physician and the hospital team comes into play.

“What I like to do is talk to the parents and child during a clinical visit about the procedure and why it is needed,” explains Dr. Beth Carter, MD, Medical Director, Intestinal Rehabilitation Program at Texas Children’s Hospital and Baylor College of Medicine. “I try to explain it in as many non-medical terms as possible. For example, if an upper endoscopy [EGD] is indicated, I might say, ‘This test allows me to look at your esophagus and stomach and the upper part of your intestines.’”

An EGD is one of the most common procedures done in children. The reasons are usually gastroesophageal reflux or inflammation of the esophagus or stomach. Dr. Carter will walk the parents and child through every detail of the procedure so they will know exactly what to expect, thus calming the anxiety that comes from the unknown. When they leave, the parents will know what type of sedation to expect (conscious sedation or general anesthesia), where the GI Procedure Suite is located, when to be there, where to park, and what to bring to the hospital. Most parents want to know if they can be with their child during the procedure. Dr. Carter explains that they can be with them in pre-op right up to the point where they start to get drowsy, and then they will go to the waiting room. However, she will also tell them how long they can expect to wait so they don’t get anxious about the length of time the procedure is taking.

By Valerie Hansen
Once a date and time that works for both the parents and for the child’s medical needs has been decided, they will meet Dr. Carter in the clinic the day before the procedure.

“We go over everything about the procedure again,” she says, “and draw any needed labs. Then my nurse will give them instructions for the next day. If it is a very young child, she’ll suggest the parents help their child pick out a toy or blanket to bring with them to comfort them. If it’s an older child, they can bring an iPod to listen to their favorite music while they are waiting.”

Dr. Carter is careful to explain procedures in terms the children and parents will understand. If she is going to use an endoscope, for example, she might explain that it is a camera on the end of a long flexible tube. She’ll say that once they are asleep and comfortable, she will put it down their swallowing tube and into their stomach to take pictures and little tiny pinches of their swallowing tube to put under the microscope to find out what is going on.

**Child Life Specialists**

If Dr. Carter identifies a child who seems nervous or anxious at that preoperative meeting, she often calls on one of the hospital’s certified child life specialists (CCLSs). Most children’s hospitals have these professionals, who are trained to promote positive coping techniques and to help normalize the hospital environment for children through play, preparation, distraction and education.

“Our goal,” explains Mary Magness, MEd, CCLS at Texas Children’s Hospital, “is to promote emotional stability and development throughout a child’s hospitalization through therapeutic activities, medical play and diversional activities.”

CCLSs are trained specifically for this role. They must go through an internship and pass a certification exam and some, like Mary, also have additional degrees. She has a bachelor’s degree in early childhood education and a master’s degree in special education. But her most important qualification is that she has a passion for working with children.

“Helping a patient understand and feel comfortable with their diagnosis in a developmentally appropriate way is so important,” Mary says. “It is wonderful to be able to show a patient that they can still have fun, be a kid, and express how they feel in the hospital.”

The CCLS staff uses photo preparation books written in developmentally appropriate language to prepare patients for medical procedures. They explain sensory experiences (what the patient will see, hear, and smell) when they are having a procedure. They also have teaching dolls and medical play equipment that they can use for education.

“If the assessment is made that medical play might show the CCLS what the patient understands about the procedure through play, we have the tools to do that,” says Mary.

**It’s All About the Children**

The entire staff at most children’s hospitals — from the physicians and nurses to the technicians placing IVs — is geared toward working with children. They avoid using phrases such as “giving a shot” or “putting in an IV” when working with young children.

“To a child, ‘getting a shot’ is going to mean something very bad,” Dr. Carter explains. “They’re going to perceive that as, ‘Why are you going to do that? Are you mad at me?’ So instead you say, ‘I’m going to give you some medicine with a
small needle.' For us it’s an everyday term to say, ‘I’m going to put in an IV.’ But to a child, what does that mean? ‘Are they going to put ivy in me?’ Instead you can say you’re going to give them medicine through a small plastic straw, because they know what that is. It may be everyday language for us, but we have to be very, very aware of what it means to the child. And the child life specialists are even better at that.”

Every detail of children’s hospitals are geared to the comfort of the young patients, from the bright colors in the décor, to cheery paintings, to areas with video games and toys the children can play with while waiting to be brought to the procedure room. The staff also is careful to keep the patients’ hospital rooms their “safe place.” If they have to have an IV inserted, they are taken to a separate room for that procedure if possible, rather than having it done in their hospital room.

“When we’re starting an IV in a school-age child, we like to have the child sit on a chair or on the parent’s lap or holding the hand of the parent, but we don’t want the parents to be the primary person who is holding the child,” Dr Carter says. “That’s the role of the healthcare provider. If it’s a teenager, they’re old enough that you can say, ‘We will be starting this IV as a way to give medicine through a small plastic line into your vein.’ You can offer the child a choice of where they want to be when you put in the IV. They can be sitting up or lying down or holding their parent’s hand even though they are a teenager.”

If the procedure is going to require a hospital stay, the parents and child are prepared for that as well. Most EGD procedures do not require an overnight stay. The exception would be if, for example, banding of a swollen blood vessel (varix) in the esophagus is needed. Whenever Dr. Carter puts a band around a varix, it is her practice to keep the child overnight for observation. If she anticipates this procedure, she will tell the parents in advance to alleviate their anxiety and to prepare them for an overnight stay.

“In most cases after an EGD,” she says, “the patient will stay an hour or so in our GI procedure suite and be released to home the same day. Generally by the time they’re home they are up and running, and they are usually eating a regular diet within a day.”

Anytime a child has to undergo a medical procedure in a hospital, it’s natural for parents to be concerned and anxious. However, knowing how caring and empathetic the professionals surrounding their precious offspring are can help alleviate that anxiety. Don’t be afraid to ask questions about any concerns you have as a parent and any that your child has. Also, be aware that CCLSs are trained to soothe your child’s fears — and thus your own.
Emily Koprucki is a bright, funny 16 year old who loves animals — and likes school okay. The backpack she wears to class contains an IV pump to keep her hydrated, but it doesn’t slow her down much. In fact, it didn’t keep her from learning how to guide a horse over some jumps.

“My doctor didn’t know if it was such a good idea,” she says with a laugh, “but it was like it [the IV pump] wasn’t even there.”

Emily was born with megacystis microcolon intestinal hypoperistalsis syndrome (MMIHS).* The condition made it necessary for her to be catheterized regularly, and to be put on parenteral nutrition (TPN)* and IV hydration* from birth — a challenge her parents, Sue and Bob Koprucki, still remember too clearly.

“Learning how to care for her and learning to infuse parenteral nutrition was really overwhelming,” Sue says. “Even though we got really great training from the nurses in our home care company, it was still so foreign.”

Connecting with Others
Sue and Bob connected with the Oley Foundation early in their confusing process of learning about TPN. As a result, not only did they no longer feel stuck out on an island by themselves, they also learned precautions and safeguards to help prevent infections and keep their baby as healthy as possible.

“You do feel alone when you first get that diagnosis,” Sue says. “You think life is going to stop. But it really doesn’t. I think the thing that helped us the most was connecting with others. In addition to the Oley Foundation, I was able to connect with a couple of local families (this was before HIPAA*). One woman whose daughter was a former TPNer was able to give me encouragement. She would assure me that, ‘yes, this is overwhelming right now but it does get better.’ She said it would get easier and that we could make life as good as we wanted to.”

TPN, Surgery — and Camp!
Emily was on TPN until she was 19 months old, when she began to get enough nutrition from enteral feeds (tube feeding)* and by mouth that she could be worked off the therapy.

“At that point I wasn’t considered to have short gut [short bowel syndrome*] because everything was intact, just not working very well,” Emily says. “But when I was nine, my large intestine perforated and they couldn’t repair it. It was done; it just disintegrated.”

* See glossary on page 21.
After the bowel perforation, Emily was put back on TPN temporarily. But while she was once again able to wean off of TPN, she had to remain on IV hydration because she now had short bowel syndrome. When Emily hit puberty, however, her body’s high caloric needs meant going back on TPN. These days she is on TPN for 10 hours overnight, and on fluids throughout the day.

Last spring, Emily underwent another major surgery. She knew it was coming and chose to have it two months before the end of the school year. That way she could work with teachers she knew to help her complete her studies and exams while she was recuperating.

“Oh, yeah, that was a fun little adventure,” Emily recalls. “I had gastroparesis,* so I had a partial gastrectomy* where they removed 85% of my stomach. They took out the pyloric valve* area as well because it had some very sharp turns and nothing could leave my stomach very easily. They took out my gall bladder* because I was having gall bladder attacks with increasing frequency. They also found that my gut was just a brick of adhesions and they didn’t know which way was up, so they had to remove all the adhesions. That’s what took the longest. They had to take down my ileostomy* and put a new one in on the other side.”

Despite the lengthy hospital stay — two weeks after surgery and an additional five days when she got a kidney infection — Emily was able to complete her schoolwork and exams by the end of the school year. She was also able to reduce her intake of some of her medications as a result, and no longer had to drain up to two liters of stomach acid twice a day.
“I think something Emily should mention,” Sue adds, “is that even with the timing and extent of the surgery, she still managed to go to camp this summer, which was really awesome.”

This was Emily’s second year at Double H Ranch (a Hole in the Wall Camp) in Lake George, New York.

“I was ready to go years before Mom was ready to let me go,” Emily teases.

Double H Ranch is designed for children and teens with medical issues that would prevent them from going to a regular summer camp. That being said, the only difference between Double H and a “regular” camp is the medical staff and trained counselors.

“While they can’t take away your medical issues,” Emily says, “they do make them seem like such a minor part of your life. They make you have the best time. It’s like a normal camp, like you aren’t different.”

“They did things like white-water rafting while infusing on IV!” Sue adds with a laugh. “Emily’s first time at the camp was two years ago, and her increase in confidence and maturity and personal growth was just immense.”

Emily’s closest friends are those she has met through the Oley Foundation, and they get to connect in person at Oley conferences and sometimes at camp as well. Of course they communicate regularly through social media the rest of the year and make trips to see each other when they can, but Oley conferences and camp are both like an annual friend reunion. Needless to say, there is not much talk of pumps and tubes when the teens get together.

Learning to Take Care of Herself

Emily has been involved in her own care from a very young age, and with college years and an inevitable transition away from her parents looming in the future, she is learning even more. She started self-cathing (putting in her own catheter) when she was five, but actually began learning the technique at a much younger age.

“Since she was a baby, I would verbalize what I was doing and why I was doing it,” Sue says. “I cathed her sometimes six times a day when she was an infant and talked through the steps every time. When she was two, she was doing it to her baby doll herself with perfect sterile technique.”

“I know how to spike® my own IV bags, and I’m on the tail end of learning to put additives in my TPN. I flush my tubes and catheter on and off; I’ve been
doing G-tube* changes and ostomy changes.* I know how to pretty much do the majority of my care, but my mom is there to back me up. Mostly,“ she admits with a giggle, “if I don’t feel like doing it. I’m a teen, what can I say?”

Emily is fascinated by the field of animal behavior and is thinking of pursuing a career as a canine behavioralist after high school. Since hospitalization is always a looming reality, she is thinking about online colleges. Even though she realizes it would require self-discipline, she thinks the field of animal behavior is so interesting that she wouldn’t have trouble wanting to do the work.

“I think it’s important for people not to let their medical issues control their life;” Emily says.“I can still be a normal kid. I can still do the things other kids do — I just have to do them differently sometimes.”

“I think people need to realize that they can choose how to look at TPN;” Sue adds. “It’s the gift of life. It really does make you healthy — it makes you stronger, it makes you able to do anything you want to do. Sometimes you have to think out of the box to do things, but you can really live. I think that’s the attitude Bob and I have ingrained in Em, and I see it in her every day.” ♦

Note: To find out more about the Oley Foundation, visit their website at www.oley.org. For information about the Double H Ranch, go to www.doublehranch.org.

*Glossary

- **Additives:** Nutrients such as vitamins and minerals that are added to a TPN solution to help meet an individual patient’s nutrition needs.
- **Enteral feeding / tube feeding:** A method of nutrition support. Nutrition is sent directly into the stomach or small bowel through a tube that is inserted into the abdomen.
- **Gall bladder:** A small organ that stores bile (a substance that aids in digestion and is produced by the liver).
- **Gastrectomy:** The surgical removal of all or part of the stomach.
- **Gastroparesis:** Nerve damage in the stomach that reduces or prevents emptying of the stomach contents into the small intestine.
- **G tube:** A gastrostomy tube. This tube is used to deliver nutrients directly into the stomach during tube feeding. With a G-tube change, the tube itself is changed.
- **HIPAA:** The Health Insurance Portability and Accountability Act, which was passed in 1996. The law provides federal protection for personal health information.
- **Ileostomy:** Surgery to create an opening from the ileum (part of the small intestine) to the outside of the body. This opening is used to discharge waste from the body.
- **IV hydration:** Fluids provided to the body through an IV.
- **Megacystis microcolon intestinal hypoperistalsis syndrome (MMIHS):** A rare condition that causes a decrease in muscle tone in the bladder and bowel. This prevents the normal passage of food, fluids and air through the body. MMIHS is congenital (a person is born with it).
- **Ostomy change:** An ostomy is an opening in the body through which digestive waste is discharged. With an ostomy change, the bag used to hold the waste is changed.
- **Parenteral nutrition (TPN):** A method of nutrition support. Nutrition is sent into the body through an intravenous (IV) line. The digestive system is not used at all.
- **Pyloric valve:** A valve that keeps material from moving back into the stomach from the small intestine.
- **Short bowel syndrome:** A condition in which the bowel is not as long as normal. The condition may be present at birth, or it may be caused by surgery. With short bowel syndrome, nutrients are not absorbed properly into the body.
- **Spike:** Spiking an IV bag means to insert tubing into the bag to allow for the administration of TPN.
2012 Small Steps to Big Steps
A Nutrition Support Consumer Teleconference Series

As a leader in long-term nutrition support, Coram understands the value of patient education, so we are pleased to offer our free, informational teleconference series, Small Steps to Big Steps. This series is a great way for nutrition consumers and their caregivers to learn about timely and relevant topics that affect them.

Join Us
Join us from the comfort of your home or office for one of our upcoming 2012 Small Steps to Big Steps teleconference calls.

Call toll-free: 866.418.5399 | Passcode 3036728726 | 7:00 pm EST/4:00 PST

January 17
Living Better! How to Minimize Long-term TPN Complications
Presented by Mark DeLegge, MD

March 20
More than Meds: Effectively Managing Chronic Pain with Multiple Therapies
Presented by Michael Joseph, MD

May 15
Oral Care for the Nutrition Support Consumer
Presented by Suzanne Plum, DDS

The Small Steps to Big Steps consumer teleconference series, brought to you by Coram Specialty Infusion Services (the presenter), is provided free of charge to the community. Opinions expressed by contributing speakers and sources are not necessarily those of the presenter. The presenter does not intend for these teleconference calls or any related program(s) to endorse any particular provider. Information contained in these teleconferences is for educational purposes only and is not intended as a substitute for medical advice. Do not use this information to diagnose or treat a health problem or disease without consulting a qualified physician. Please consult your physician before starting any course of supplementation or treatment, particularly if you are currently under medical care. Never disregard medical advice or delay in seeking it because of something you have heard in this teleconference. © 2012 Coram Specialty Infusion Services. All rights reserved. No part of these teleconferences may be disseminated, distributed, or reprinted without prior written permission of the copyright owner. All service marks, trademarks, and trade names presented or referred to in these teleconferences are the property of their respective owners.
July 17

**Input That Stays Put**
Presented by Carol Ireton-Jones, PhD, RD, LD, CNSC and Therese Austin, MS, RD, LD, CNSC

September 18

**Healthcare Reform: What Consumers Need to Know**
Presented by Lisa Getson, Executive VP Government Relations and Corporate Compliance

November 20

**New Technologies and Innovations for the HPEN Consumer**
Presented by Melissa Leone, RN, BSN

---

**Missed A Call?**

If you missed a call, you can listen to past calls at WeNourish.com/consumers/events.aspx.
Pediatric Intestinal Failure-associated Liver Disease:
Causes, Prevention & Treatment
By Robert S. Venick, MD
Background
The initiation of intravenous nutrition, also known as parenteral nutrition (PN), in the 1960s was a life-saving development that has profoundly impacted the prognosis and quality of life of numerous children with intestinal failure (IF). IF is defined as the inability of the small bowel (intestine) to adequately absorb nutrients, fluids, and electrolytes needed to support normal growth and development. Causes of IF among children include surgical short bowel syndrome (SBS)*, motility disorders,* and enterocyte abnormalities.

One of the goals in treating pediatric IF patients is to provide the support needed to allow children to achieve independence from PN, a process referred to as intestinal adaptation. Adaptation can be as variable and unique in its course and duration as each of the individual children with IF. This process is especially important because while PN can be life-sustaining, its long-term use may be associated with potentially life-threatening complications. These complications include intestinal failure-associated liver disease (IFALD).

Risk Factors and Causes of IFALD
IFALD is best thought of as a disease spectrum ranging from a mild biochemical elevation in liver function tests (>1.5 x the upper limit of normal for two or more weeks) to biopsy-proven cirrhosis.* Those patients most vulnerable to developing IFALD include premature infants with a birth weight of <1 kg, and children with IF resulting from surgical causes of SBS.1,2 Also, as many as 50% of children receiving PN for over two months will develop some degree of IFALD.3 That being said, there are a number of patients who have been PN-dependent for over 20 years who do not have significant liver disease.

The cause of IFALD remains unknown, but potential risk factors include:
- being born prematurely,
- small bowel length of <40 cm,
- lack of an ileocecal valve,*
- inability to tolerate significant calories via the gastrointestinal (GI) tract,
- bacterial translocation,*
- multiple episodes of infection,
- potential deficiencies in PN infusates,*
- excess calories, carbohydrate or fat provided by the PN, and
- potentially the type of intravenous fat.4-6

Prevention and Treatment of IFALD
A multidisciplinary approach is essential to preventing and treating IFALD. Coordinated care is needed among pediatric gastroenterologists, surgeons, nurse specialists, dietitians, pharmacists, and social workers specialized in and devoted to caring for these children. Frequent follow-up and communication between families and their healthcare teams is especially important. Relatively few studies are available in the field of prevention and treatment of IFALD. This means that treatments are mostly derived from expert opinion and practice. These treatments include:

Methods to Improve Absorption in the GI Tract
Enteral absorption is the ability of the intestinal tract to absorb nutrients. Increasing enteral absorption is a key goal in the prevention and treatment of IFALD, as it helps reduce the need for PN and thus decreases the risk of IFALD.

Enteral feeds (tube feeding) stimulate excretion of bile from the liver. This helps improve nutrient absorption, reduce TPN dependency and keep

* See glossary on page 26.
the liver healthy. Caregivers should make persistent attempts to increase tube feeding to the maximum tolerable amount. This is typically 30 cc of stool output/kilogram of body weight/day in a child with an ostomy,* and 20 cc/kg/day in a child without an ostomy. Besides stool output, other factors that the medical team takes into consideration in its decision to increase tube feeding include:

• the presence or absence of abdominal distension (swollen belly),
• vomiting,
• weight gain,
• skin breakdown around the ostomy site or diaper area, and
• fluid and electrolyte status.

It is also important to discover the optimal plan for nutrition support for each of these unique children with IF. This includes determining the best:

• regimen (breast milk, elemental or semi-elemental formula*, standard formula, or an age-appropriate diet),
• route(s) of delivery (by mouth, by gastrostomy tube into the stomach, or directly into the small bowel), and
• mode (bolus* vs. continuous* feeds).

For children with IF who have ostomies, surgery to remove the ostomy and restore the GI tract to a continuous system may be done. Performing this surgery as early as possible has been shown to help improve nutrient absorption and prevent worsening liver disease.4 For children with segments of intestine that are too narrow, too wide, or have decreased motility, additional surgeries such as bowel tapering or lengthening procedures may help increase enteral absorption.7,8

**Glossary**

- **Bacterial translocation:** The movement of bacteria from the GI tract into the bloodstream.
- **Bolus feed:** A method of tube feeding where nutrition is delivered four to eight times per day, for 15 to 30 minutes at a time.
- **Cholestasis:** A condition in which the flow of bile from the liver into the gastrointestinal tract is slowed or blocked.
- **Cirrhosis:** A chronic disease in which normal liver cells are damaged and replaced by scar tissue.
- **Compassionate use:** A federal program that allows access to experimental drugs in certain situations.
- **Continuous feed:** A method of tube feeding that delivers nutrition continuously over an extended period, often up to 18 hours at a time.
- **Elemental formula:** PN formula that is broken down into its most basic components.
- **Enterocytes:** Cells in the lining of the small intestine.
- **Ethanol lock therapy:** A treatment that may help reduce infections in central venous catheters.
- **Hyperinsulinemia:** High levels of insulin in the blood.
- **Ileocecal valve:** A fold of tissue that keeps material from moving back into the small intestine from the large intestine.
- **Infusates:** Contents of a parenteral nutrition formula.
- **Motility disorders:** Problems with movement of food and waste through the digestive tract.
- **Ostomy:** An opening in the body through which digestive wastes are discharged.
- **Phytosterols:** Compounds made from plants that may help reduce blood cholesterol levels.
- **Probiotics:** Dietary supplements that contain live bacteria or yeast. Probiotics increase the amount of normal bacteria in the GI tract and may help improve digestion.
- **Surgical short bowel syndrome (SBS):** A condition in which the bowel is not as long as normal due to surgery. With SBS, nutrients are not absorbed properly into the body.
help slow the movement of nutrition through the GI tract. Another medication, ursodeoxycholic acid, can have a positive effect on liver function and can help avert liver disease associated with long-term PN use.

Other medications that may be helpful include antibiotics that target and treat small intestine bacterial overgrowth (SIBO). SIBO is a phenomena to which children with short-bowel syndrome are prone. SIBO can lead to inflammation of the lining of the GI tract, the movement of bacteria from the GI tract into the bloodstream, and an extended need for PN. Cycles of antibiotics delivered via the GI tract, referred to as bowel decontamination regimens, have been shown in some studies to help improve enteral absorption and improve liver function tests. Probiotics are used by some practitioners who care for children with intestinal failure. However, they must be used with caution in young children with central venous catheters (CVCs) due to the increased risk of infection they present.

Infection Control
Strategies that can help reduce or eliminate CVC infections are critical to the successful delivery of PN and avoidance of IFALD. Such strategies include working with clinical nurse specialists to review vigilant, proper, sterile techniques for accessing, cleaning and caring for CVCs and catheter insertion sites. In addition, prompt recognition and treatment of line infections, as well as removal and replacement of CVCs when needed, are key components of care for children with IF. Antibiotic or ethanol lock therapy has been employed in children at high risk of developing bloodstream infections. Additionally, newer strategies aimed at reducing CVC infection rates include the use of a Biopatch — an antiseptic agent — and the advent of newer CVC caps. These relatively novel therapies have not yet been adequately studied.

PN Strategies
Avoiding delivery of too many calories and too much dextrose (sugar) and fat in PN is an important concept in preventing IFALD. Along these same lines, infusing PN over a shorter period of time can help improve cholestasis. This practice of cycling PN potentially gives the body a “rest” from the continuous infusion of calories, and helps avoid a state of hyperinsulinemia. Using pediatric-specific formulations of PN that include certain amino acids (such as taurine) has also been touted. Decreasing or avoiding aluminum and manganese additives in PN may also decrease the risk of liver damage.

There is now research that suggests that decreasing the amount of lipid (fat) or changing the type of IV lipid given to children receiving PN may improve or reverse IFALD. Historically in the U.S., the available IV lipid formulations have been safflower- and/or soybean-based. These formulas contain high concentrations of omega-6 fatty acids.
acids (O6FA) and phytosterols* and minimal amounts of vitamin E, and have been prescribed at doses as high as 4 g/kg/day. On the contrary, IV fish oil — a 100% omega-3 fatty acid emulsion — is prescribed in other parts of the world, including Europe and Asia. IV fish oil is available in the U.S. under research protocols approved by the Food and Drug Administration (FDA) and Institutional Review Board (IRB), as well as for compassionate use.* Recent experience has demonstrated that when standard O6FA products are replaced with fish oil (commercially available as Omegaven®) and dosed at 1 g/kg/day, liver injury can be reversed in many children.11-13 Keep in mind that because intravenous O3FA is a relatively new therapy, the long-term results of Omegaven remain unknown, especially in children who are unable to wean off of PN.

Transplantation
For children who develop advanced or end-stage IFALD, known as cirrhosis, combined liver-intestinal transplant is the only option. Such transplants are a major undertaking performed at only a handful of specialized centers throughout the U.S. These procedures have challenging, but in certain cases potentially life-saving, long-term outcomes.

Conclusion
IFALD can be a significant source of health problems for children who are dependent on long-term PN. A multidisciplinary approach aimed at achieving the best absorption of nutrients and minimizing infections is critical to prevention and treatment. Several new therapies offer potential benefit to children in this field, but long-term studies and data are still needed at this time.♦

References

* See glossary on page 26.
Don’t encourage long mealtimes.
Don’t let kids throw food.
Don’t get upset when your child refuses food.
Don’t reward your child for refusing food (such as by offering ice cream instead).

Increasing the Variety of Foods in Your Child’s Diet

If your child is eating, you’ll want to gradually introduce him or her to new foods. Keep in mind that on average, it can take 10–15 exposures of a new food before it is accepted, and if your child has a background of feeding difficulties, it could take 20–30 times or more.

To start, offer an unfamiliar food along with a familiar, preferred food. The new food should be similar to the familiar food in color, size, shape and/or texture. This technique will encourage your child to try a greater range of food types. To gradually introduce your child to new foods, try the food list below, which contains foods that you can give your child in a step-wise approach, with each food resembling the last in color, size, shape or texture:

1. Kiwi lime yogurt or kiwi lemon yogurt
2. Lemon licorice (similar flavor and color)
3. Cherry licorice (similar texture, size and shape)
4. Beef jerky (similar color and texture)
5. Bologna strips (similar color, both meats)
6. Turkey strips (similar texture and temperature, both meats)
7. Pina colada licorice — white (similar color, shape and size)
8. Breadstick (similar color, shape and size)
9. Club cracker (similar color, texture, size and flavor)
10. Apple slices — peeled, sliced thin, cut into rectangles (similar color, shape and size)
11. Whipped cream (similar color and temperature)
12. White grape/apple juice (similar color and temperature)

Here are additional steps, to be taken in order, that can help you increase the variety of foods your child enjoys:

1. Identify foods that your child prefers and ask the child to take a bite. Starting with a preferred food serves as a “natural reinforcer,” encouraging your child to start eating.
2. When your child requests a preferred food, ask the child to take a bite of another preferred food first.
3. Ask your child to take a bite of a preferred food along with a bite of non-preferred food, and provide encouragement. You may want to start more slowly and expect smaller steps, such as tolerating non-preferred foods on the plate, then smelling them, then touching them. Any progress should be encouraged.
4. Gradually increase requests to eat non-preferred foods while decreasing requests to eat preferred foods — but always end on a positive note!

Use these tips as a guide to help you become a supportive feeding teacher, but also reach out to your child’s medical staff for helpful recommendations. Remember to celebrate every little step that is conquered, stay positive, and listen to your child. You can help your child enjoy mealtime and an increased variety of foods, and move your child further to reducing his or her nutrition support dependence.

Reference

Giving Our Children Wings:
A Journey of Independence for HPEN Families

All parents must face “letting go” at many stages of their child’s life. As a parent of a soon-to-be 30-year-old HPEN (home parenteral or enteral nutrition) consumer, I can honestly say that letting go and watching my daughter fly solo has been scary at times. But I can tell you that with support from others and the knowledge that you have prepared your child for each new phase the best you can, you may find letting go to be one of the most exhilarating feelings you will ever experience.

Preparation Along the Way
Your child’s first steps toward independence are when he or she goes to school — and this is an opportunity to educate the educators. Planning ahead and working with the school to teach administrators the unique needs of your child can ease fears on both your side and theirs, and help them ensure a pleasant school environment for your child. See page 7 for more tips on easing your child into school. These efforts will be well worth it, because seeing your child happy and safe at school is very rewarding.

Another opportunity for your child to fly solo is at camp. Thanks to the generous spirit of the late actor Paul Newman, there are camps from California to Connecticut that focus on fun for the medically fragile child. Designated weeks focus on different medical needs, including nutrition support needs. Information is available at www.holeinthewallcamps.org.

My Daughter Spread Her Wings
When my daughter had to be hospitalized, I was the proverbial “Mama Bear.” I watched everything and everyone. I’m sure I was overprotective, but for kids like ours, that can be a good thing. When my daughter was old enough to be independent, you can imagine how fearful I was to let go of being the chief caregiver and turn it over to my daughter.

In the beginning, I had her simply gather all the supplies and set out the bag to get it to room temperature. In a matter of three short months, she was able to safely do her own TPN hook-up and disconnect, adding her vitamins and other additives. She could do nearly everything for herself. Soon she was on auto-pilot. Occasionally, when she had an evening event to attend, I would surprise her and have everything ready for her when she got home. She really considered it a treat, and I got much joy out of being able to
give her a night off from the routine. It is true that imitation is the greatest compliment, and I can say my daughter imitated me and now has developed her own routine, which I think is better than mine. When she needs medical attention, she can now be her own Mama Bear!

With a lot of help and support, my daughter graduated from high school and went away to college. This was probably the scariest and the happiest time of my life. It was hard to imagine that the child who at times was so fragile had become a young woman and was moving out to live in another city. I remember telling her how proud I was of her and that I would always be there to help her, especially when she was acutely ill. My darling daughter looked at me and said, “Mom, I am never cute when I am sick!”

That was almost 12 years ago and yes, there have been times when she needed me and I gladly stepped in. But now, with her help, I know when to step away.

Soaring On Their Own

Giving our children wings is one of the greatest gifts we can give them. Realizing the limits your child has and recognizing his or her strengths takes trial and sometimes error. It is much like baby birds in the nest. The parents feed and nurture the baby chicks, and then start to nudge them out to teach them how to fly. The first flights are short and not always successful, but eventually the babies learn. The one thing I can promise is that when you teach them to fly solo, they always remember how to migrate back to you. ◆
Consumer Contacts

Celebrate Life Magazine
To submit stories, comments, and suggestions for Celebrate Life, email: celebratelife@coramhc.com

WeNourish.com
- General information about the Nourish Nutrition Support Program
- Educational tutorials, videos and downloadable patient education tools
- Consumer events and teleconferences
- Online archive of Celebrate Life magazine
- Consumer resource links
- Local Coram branch maps and information

877.WeNourish (877.936.6874)
Call to speak to a TPN or tube feeding representative.

Nourish Advocacy Line
To reach a dedicated consumer advocate, call: Toll-free 866.446.6373

Informational Teleconference Series
To view a schedule of upcoming teleconference topics and times, visit: WeNourish.com/consumers/events.aspx

Connect With Us
facebook.com/coramhc
twitter.com/coramhc

Celebrate Life
For Home TPN and Tube Feeding Patients

555 17th Street, Suite 1500, Denver, CO 80202

Celebrate Life is a publication of Coram Specialty Infusion Services.