INSIDE

Back in the Saddle: The Good, the Bad and the Beauty of Being a Caregiver

A Few Thoughts About Exercise and Fitness

Surf the Waves of HPEN

Your Venous Access Device
3 Editor’s Note
Editor-in-Chief Carol Ireton-Jones talks about the upcoming Oley conference in San Diego, Calif., and gives an overview of some of this issue’s articles.

4 Surf the Waves of HPEN
Notes about the upcoming Oley Foundation’s Annual Conference in San Diego.

5 Back in the Saddle
The Good, the Bad and the Beauty of Being a Caregiver
After her 26-year-old daughter was injured in a car accident, Coram Partner Linda Gravenstein was suddenly thrust into the role of caregiver. She shares her thoughts on how she coped with the crisis.

6 A Few Thoughts About Exercise and Fitness
Personal trainer and lifestyle coach Debbie Baker gives advice about how to attain fitness goals that at first may seem impossible.

8 Your Venous Access Device
Dr. Ezra Steiger of the Cleveland Clinic provides important information about the various types of venous access devices used in HPN therapy and the benefits and disadvantages of each one.

10 Home Parenteral and Enteral Nutrition Support Educational Conference Call Series
In order to educate and empower home nutrition consumers, Coram is pleased to present the 2008 schedule for its Educational Conference Call Series for HPEN consumers.

11 Fun Stuff
Delicious shrimp bisque recipe for HPEN consumers and families, plus a word search puzzler.
Editor’s Note

Dear Consumers,

Happy spring! Hopefully the trees are budding where you are and the sun is shining a bit more often. This issue of the newsletter “springs” into action with some great articles for you.

On page 8, Dr. Ezra Steiger provides some information on your venous access device. Dr. Steiger is from the Cleveland Clinic and has been a leader in the care of parenteral and enteral nutrition patients in the hospital and home for many years. He is a dedicated clinician and caring physician. Some of you may know him from his time on the board of the Oley Foundation, or as president of the American Society for Parenteral and Enteral Nutrition.

Speaking of the Oley Foundation, the 2008 conference is not far away — June will be here soon! We are planning our booth and look forward lots of fun during the meeting in San Diego, Calif. If you plan on attending or are just thinking about attending, please feel free to call on Linda Gravenstein, our consumer advocate, to help you with the ‘ins’ and ‘outs’ of traveling to the meeting. Also, your local Coram branch will be happy to help you make arrangements for traveling with your nutrition supplies for that trip, or any travels you are considering for the future.

This month, Linda shares her insights gained from her recent return to the role of caregiver after her daughter was injured in car accident. And personal trainer Debbie Baker both encourages and inspires us to add some activity to our lives in her article about exercise.

Take care,

Carol Ireton-Jones

Carol Ireton-Jones
Editor-in-Chief
Surf the Waves of HPEN
The Oley Foundation’s Annual Conference

Surf’s up! We can’t wait to attend the Oley Foundation’s Annual Conference in San Diego, Calif. from June 26-30. This year is especially exciting as the Oley Foundation celebrates its 25th anniversary helping and improving the lives of all consumers and their families dependent on HPEN. At Coram and Apria, we are excited to share in this historic anniversary as we also celebrate our own 25th anniversary as a sponsor of this dedicated non-profit organization.

The Oley Foundation is the “go to” organization for all who depend on HPEN. This extraordinary group of people work diligently all year long to prepare for this annual conference, bringing together the finest clinicians from all over the world to present the most current and ground-breaking information. These four days are packed with presentations, exhibits, social events, planned youth activities and opportunities to make lifelong friends. Meals and activities are provided through corporate sponsorships, leaving only the hotel and travel expenses to be covered by the attendees. This year the host hotel is the Mission Valley Marriott in San Diego. They are offering special discounted rates for Oley conference attendees. Information about the annual meeting and hotel accommodations are available through the Oley Foundation’s website at www.oley.org or their toll-free number 800.776.OLEY.

Each year during the annual conference, Coram celebrates our partnership with our HPEN consumers and their families by hosting a Family Dinner. This year we are proud to include Apria and their family of consumers in our celebration. The dinner will be held during the annual conference with all Apria and Coram consumers cordially invited to attend. This occasion provides an opportunity to catch up on the events of the last year, welcome new consumers to our family and learn a little more about each other. We will be in touch soon with more information about the dinner.

We sincerely hope you are planning to attend this fun-filled and educational conference. If so, please help us welcome you to San Diego by contacting either Linda Graventstein or your local branch nutrition support team. We are here to make your travel experience as safe, easy and enjoyable as possible. If you have any questions or concerns about this trip, or any upcoming travel plans, please call 866.4HomePEN (866.446.6373) or email Linda at gravensteinl@coramhc.com.
Back in the Saddle
The Good, the Bad and the Beauty of Being a Caregiver

by Linda Gravenstein, Coram Partner

On a recent sunny morning with clear blue skies, my daughter Megan left my home to drive to her house a few miles away. The holidays were fast approaching and I had a day packed with projects and chores. With one phone call, my world came apart. Megan had been in a serious car accident and was being taken to the largest trauma center in the area. A mother’s greatest fear had come true.

When I arrived at the hospital, I was able to see Megan and was informed that her injuries were serious but not life-threatening. While the doctors had tended to her broken bones, I informed them that Megan was an HPN consumer. Her GI surgeon just happened to be on staff at the trauma hospital, so I had them call him before they did her abdominal CAT scan. I was so glad they didn’t find any internal injuries, but she did have two broken legs and a broken hand. We began thinking about what was needed to care for her orthopedic injuries and HPN, and decided she should move into my house when she left the hospital. Megan was discharged to my home a few days before Christmas, stable, but she was supported by a metal apparatus which left her unable to take care of her daily HPN. She needed support and care. Suddenly, I was a once again a hands-on HPN caregiver.

I knew the mechanics of what needed to be done, but to actually get back in the saddle and do it was a little difficult at first. I was constantly double-checking myself and my techniques. All those things we say about the HPN line being a lifeline were a reality for me.

I am glad to report that Megan is healing and getting better each and every day. It is a joy to know that I was able to help her through this crisis. This experience helped me to realize a few things that I would like to share with you:

♦ A clean and healthy house is not necessarily a neat one.
♦ Organizing supplies helps to avoid unnecessary panic and urgent deliveries.
♦ Friends and family want to help — they just need you to tell them what to do. If you need time with loved ones, ask them for help with housework.
♦ Take time for yourself. You are more efficient when you are rested. Check with agencies who provide four-hour care breaks. Even one day a week for four hours can be helpful. And you don’t have to go out — you can just sleep or watch TV on your own.
♦ It is okay to be frustrated, mad or sad. Go to your closet, bathroom or backyard and let it out!

continued on page 7
With the start of another new year, it seems as if we all have a list of resolutions or goals — many include the “E” word, exercise. How have you done so far? If you made a resolution to exercise or to be more active, then good for you! We know that activity and movement are important to good health. While many of you won’t be training to become a bodybuilder, you do want to build the best body you can at your own level. Debbie Baker, a personal trainer and lifestyle coach, offers us encouragement and inspiration in setting and meeting our fitness goals. Be sure and speak with your doctor to determine what type of activity or exercise is best for you before starting any program.

It’s Not the Destination — It’s the Journey

by Debbie Baker

As a personal trainer and lifestyle coach, I hear much about resolutions or goals and am often asked to help my clients find ways to achieve them. Sometimes we succeed, sometimes we don’t. One important thing I have learned from working with people in their fitness quests, and from my own life, is that goals are just that — goals. They should spur you to take action to meet them, but they should also be somewhat realistic and attainable. The old I’m going to lose 40 pounds this month and run 5 miles every day even though I haven’t left the sofa in a year just isn’t going to work. You will wind up frustrated — not to mention sore, hungry, and exhausted — and abandon that lofty goal in about a week, no doubt having to console yourself with cake and ice cream.

In addition to being realistic and attainable, your goals should be set and met throughout the year — not just on New Year’s Day only to be forgotten by the time the groundhog makes his debut. Some goals can be short-term and some long-term. When I turned 42 (I am 48 now), my long-term goal was to compete as a bodybuilder by the time I was 45. Having worked out regularly for many years, I had a solid foundation so this was realistic for me. My short-term goals involved the specific training and dietary cycles that were necessary for me to achieve this. I happily competed during the summer of my 45th year and have been competing ever since. Sometimes I do well, but sometimes I don’t fare so well! I do keep trying and learning what works for me. Once when I was discouraged by my placing at a contest, a friend asked me why I kept doing this if I was so disappointed. Why would I continually do all the cardio, heavy lifting and strict diet that was required if my placing didn’t improve? I told her that I had discovered I love the journey just as much, if not more, than the destination.

You don’t have to be a bodybuilder to find the excitement and enjoyment that I obviously get from my sport. That’s the amazing thing about exercise and fitness — anyone who can move can benefit from it. If you are physically able, go for a walk — even if at first it’s only around the bed or to and from
the mailbox. Ask a friend to go with you (better yet, hire a trainer!). Do chores around the house to music. If you can’t move your legs for whatever reason, then move your arms. Just move! Exercise releases natural mood-elevating endorphins. I can honestly say that I have never been in a bad mood after exercising (maybe before).

Another key factor in your fitness success is something I tell my clients frequently — consistency. No weekend warrior mentality. Be consistent and sensible about fitness. A positive attitude serves you well in whatever you do. Once you have achieved a weight-loss or exercise goal, you have to work to maintain it and continually improve yourself. And always remember that fitness is a journey, not a destination. So make your journey fun. Fill it with family, friends and pets and make the most of every day you are privileged to live.

Debbie Baker is a personal trainer and bodybuilder living in Plano, Texas. She is married and is the mother of two daughters ages 15 and 19 and an 8-year-old Yorkie.

I have been giving advice to other caregivers for the last few years about being a caregiver. I equate my advice to that of an older mom to a new mother. I have the experience and I know what to do, but I had forgotten what it feels like to actually have to do it. Now I know yet again what it is to be a hands on caregiver. It has been my privilege to do this for Megan and she has been a model patient. I also have a great support group consisting of my husband and friends — they didn’t know they would become the caregiver’s caregiver, but they have.

I hope this article helps those of you who are caregivers every day. I personally appreciate you more than you will know. If you have a story or any helpful hints that you would like to share, please email me at celebratelife@coramhc.com or call me on the HPEN hot line at 866.4HomePEN.
Your Venous Access Device

by Ezra Steiger, MD, FACS, CNSP, Cleveland Clinic, Cleveland, Ohio

Introduction

There are many therapies that are provided via catheters placed in veins for prolonged periods of time. Some of these are Home Parenteral Nutrition (HPN), home intravenous hydration and home intravenous antibiotic therapy. A reliable and safe device placed by an expert clinician that is well cared for and appropriately monitored will enable these devices to be safely used for many years. Most of you reading this article are receiving HPN, however, you may also be receiving other IV therapies. This article will provide information on and consideration regarding the types of devices used for HPN.

Choosing a Reliable and Safe Device

The major types of venous access devices are tunneled-cuffed catheters such as the Hickman catheter, subcutaneous ports and peripherally inserted central catheters (PICC).

Venous Access Devices

The following table summarizes the characteristics and benefits of each of these venous access devices.

<table>
<thead>
<tr>
<th>Device</th>
<th>Location</th>
<th>Needle skin puncture required for access?</th>
<th>Usual Durability</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hickman (Tunneled-cuffed catheter)</td>
<td>Under skin and exit site</td>
<td>No</td>
<td>Months to years</td>
<td>Infections can often be treated without removing device</td>
</tr>
<tr>
<td>Port</td>
<td>Under skin</td>
<td>Yes</td>
<td>Months to years</td>
<td>No exit site</td>
</tr>
<tr>
<td>PICC</td>
<td>Under skin and exit site</td>
<td>No</td>
<td>Weeks to months</td>
<td>Inexpensive, safe bedside placement possible</td>
</tr>
</tbody>
</table>

Prior to deciding which type to use, consumers should discuss the advantages and disadvantages of each with their physician. If therapy is to be used for more than four to eight weeks, the more durable tunneled catheters or ports should be considered. There is no difference in the incidence of infection or dysfunction between tunneled catheters and ports, but tunneled catheters that become infected can usually be treated with antibiotics while infected ports almost always have to be removed. PICC lines are satisfactory if infusion therapy duration is less than two months. They are associated with an increased incidence of dysfunction such as obstruction and withdrawal occlusion, and an increased incidence of venous thrombosis or blood clot formation. You have the ultimate right to choose the device that you feel meets your needs, but the more informed you are, the better the choice will be.
**Venous Access Device Placement**

Prior to placement of your venous access device, the exit site should be determined and marked in a place where it can be easily cared for and accessed by the patient or caregiver. In addition, a determination should be made as to the number of lumens required to accommodate the potential needs of multiple infusion therapies. A lumen is the visible opening of the device’s channel(s). In general, it is desirable to use the least number of lumens possible to minimize the risk of infection. If you are receiving HPN, we usually advise using a single lumen device.

In most hospitals, a surgeon or interventional radiologist has the skills necessary to place long-term venous access devices. However, institutions that care for many patients on HPN have more experience and expertise in access device placement. When possible, surgeons or interventional radiologists in these institutions should be consulted for venous access device placement.

Placement can occur in the operating room or the interventional radiology suite. Anesthesia makes the insertion procedure very comfortable, and the amount of post-insertion discomfort is easily controlled. The vein that is used to gain access to the central venous system is usually a jugular vein at the side of the neck or the subclavian vein under the clavicle.

**Summary**

A venous access device that is best for you and your infusion needs should be discussed with your HPN clinicians prior to placement. Proposed catheter exit sites should be predetermined and marked. Expertise in device placement by a surgeon or interventional radiologist who has extensive experience regarding the needs of HPN patients should be considered in deciding where to have your venous access device. Proper positioning of the catheter tip can help to minimize catheter dysfunction and complications.

Proper care and maintenance of your venous access device and its appropriate monitoring will be covered in a future issue of this newsletter.
In Invitation to the Consumer Community

Coram is a consumer-focused company that strives to educate and empower the consumers it serves. To that end, Coram is pleased to present to you the 2008 Home Parenteral and Enteral Nutrition Support Educational Conference Call Series.

The Educational Conference Call Series is a great way to share, listen and learn about topics that affect you as patients and consumers. You never have to leave your home and there is no charge for participating. Coram’s goal is to provide you with information and to give you an opportunity to interact with others with similar interests and concerns. To participate in a conference call, simply follow these steps:

- Call 866.213.1962 approximately five minutes before the call is scheduled to begin
- When prompted, enter the seven-digit conference call access code 9917809

We look forward to having you!

Conference Call 2008 Calendar

All conference calls are held on Tuesday evenings at 7:00 EST, 6:00 CST, 5:00 MST and 4:00 PST. Arizona calls will be one hour earlier during daylight savings time.

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Speaker</th>
<th>Access Code</th>
</tr>
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<tr>
<td>April 15, 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Bob H. Saggi, MD</td>
<td>9917809</td>
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<td>May 20, 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Robin Nagel, RD and Linda Gravenstein, Coram Partner</td>
<td>9917809</td>
</tr>
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<td>June 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Megan Gravenstein, Coram Consumer</td>
<td>9917809</td>
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<td>August 19, 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Mark DeLegge, MD, Medical Director, Coram</td>
<td>9917809</td>
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<td>September 16, 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Mark DeLegge, MD, Medical Director, Coram</td>
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<td>October 21, 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Mark DeLegge, MD, Medical Director, Coram</td>
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<td>November 18, 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Mark DeLegge, MD, Medical Director, Coram</td>
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</tr>
<tr>
<td>December 2008</td>
<td>Intestinal Rehabilitation vs. Intestinal Transplant — Which is Right for You?</td>
<td>Mark DeLegge, MD, Medical Director, Coram</td>
<td>9917809</td>
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</tbody>
</table>

For more information regarding the Conference Call Series, contact:

Linda Gravenstein, Coram Partner: Toll-free 866.4HomePEN (866.466.6373) • Cell 832.296.7188 • Email gravensteinl@coramhc.com

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Shrimp Bisque
From Becky Weseman, RD, CNSD, The University of Nebraska Medical Center IRP Program

Ingredients
- 3 tbsp. Promise® margarine
- 1 rib celery, finely minced
- 1 carrot, peeled and finely chopped
- 3 green onions, minced
- ½ tsp. thyme
- 1 tsp. minced garlic
- Dash pepper
- 16 oz. clam juice
- 2 medium potatoes, peeled and diced
- 1 cup water
- 3 cups soy milk
- ¼ cup flour
- 1 lb. pre-cooked shrimp

Instructions
Melt margarine in a six-quart pan. Add celery, carrot and onion; sauté until slightly tender. Add spices, clam juice, water and diced potato. Cook until potatoes are tender. Add flour to soy milk and blend, then stir into vegetable mixture. Add shrimp and heat thoroughly, being sure not to let the mixture boil.

Yield: Approximately seven 8 oz. servings.
Per serving: 230 calories; 17g carbohydrate; 15g protein; 7g fat.