

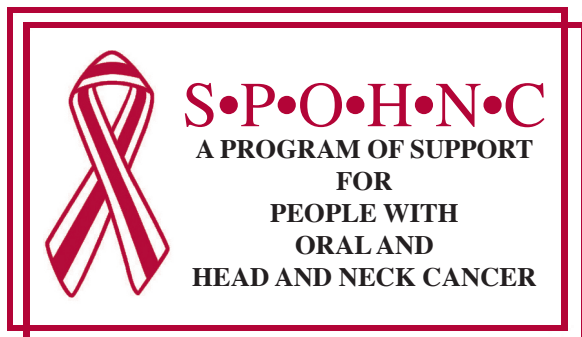
NEWS FROM S·P·O·H·N·C



VOL. 24 NO. 5

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.

FEBRUARY 2015



Choosing the Right Tube for You

Lauren Schwartz, MD

Foreword

Head and neck cancer (HNC) is a major healthcare problem for the United States. These cancers usually involve the oral cavity, oropharynx, nasopharynx, hypopharynx and larynx. The major risk factors for the development of oral, head and neck cancer are the use of tobacco or alcohol and certain viral infections (HPV). Patients may present with sore throat, hoarseness, ear pain, odynophagia (painful swallowing) and dysphagia (difficulty swallowing). On physical examination patients may have enlarged lymph nodes and fullness in the neck region. There may be difficulty chewing and opening the mouth.

The treatment of HNC involves some form or combination of chemotherapy, radiotherapy and surgery. These treatments often have significant side effects which can impact the ability to eat or drink, and can have a profound effect on a patient's nutritional state. As with many cancers, HNC may be associated with anorexia (decreased appetite) and difficult or painful swallowing which, in turn, may limit or eliminate the intake of fluid, food and medication by mouth. Avoiding nutrient deficits and malnutrition is important for improving clinical outcomes and preventing patient debilitation and decreased quality of life.

Malnutrition and associated functional debilitation can prevent or delay treatment. The use of a feeding tube is often necessary before, during or after the treatment to provide a route for water, nutrition and medicines if you are unable to adequately consume these substances orally. Feeding tubes may be as simple as a tube passed through the nose into the stomach (nasogastric tube) or a tube passed through the skin surface into the stomach by a procedure (percutaneous endoscopic gastrostomy (PEG) or surgical gastrostomy). Many clinicians recommend placing a feeding tube electively prior to the start of any treatment. The decision of if and when to place a feeding tube requires an

informed discussion between the patient and their clinicians so a reasonable and acceptable decision can be achieved.

Mark H. DeLegge, MD - Professor of Medicine, Medical University of South Carolina, Senior Medical Director, Integrated Pharmacy Solutions, Baxter Healthcare.

Types of Tubes

The choice of tube depends in part on whether the tube is needed on a short-term or long-term basis. Short-term tubes include the nasogastric (NG) and naso-jejunal (NJ) tubes, which go through the nose and end either in the stomach (NG) or small bowel (NJ). Tubes intended for more long-term use include the gastrostomy tube (PEG, G-tube), gastro-jejunostomy tubes (PEG-J or G-J tubes), and jejunostomy tubes (PEJ, J-tube).



Lauren Schwartz, MD

Placing a Tube

Tubes can be placed in a variety of ways. They can be placed surgically by a surgeon; under x-ray guidance by an interventional radiologist; or during an endoscopic procedure by a gastroenterologist.

NG- and NJ-Tubes

Short-term tubes include those that pass down the nose and into the stomach (NG-tube) or into the small intestine (NJ-tube). These tubes must be removed after four to six weeks to avoid complications, such as sinusitis or tissue breakdown within the nasal cavity.

An NG-tube can be placed at the bedside. An NJ-tube, however, is typically placed under endoscopic guidance because the tube must pass beyond the stomach outlet and into the small bowel. Several approaches can be used to position the NJ-tube.

One approach entails placing an NG-tube and then inserting an endoscope along with a forceps or snare device. Another approach is to put a guide wire into the small bowel through a channel in the endoscope. The wire remains in place as the endoscope is withdrawn, a tube is passed over the wire, and then the wire is removed while the tube stays in place. A final approach is to pass an endoscope into the small bowel and feed a small caliber (3 mm) NJ-tube through the endoscope channel into the small bowel. The doctor then gradually advances the tube into the small bowel as the endoscope is withdrawn, leaving only the tube in place.

Long-Term Tubes

Long-term feeding tubes can remain in place as long as they are needed. These tubes can be divided into two categories: pre-pyloric

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and post-pyloric tubes. The pylorus is the stomach’s outlet into the small intestine. A pre-pyloric tube refers to a tube extending into the stomach, and a post-pyloric tube is one that extends through the stomach into the small intestine. The two types of post-pyloric tubes include the gastro-jejunostomy tube and the jejunostomy tube.

Gastrostomy Tube

A gastrostomy tube is a tube that passes through the abdominal wall into the stomach. Often, the initial gastrostomy tube is placed endoscopically by a gastroenterologist. A tube placed this way is called a percutaneous endoscopic gastrostomy, or PEG, tube. To place a PEG tube, the doctor advances an endoscope into the stomach. Once in the stomach, a light at the end of the endoscope can be seen on the surface of the patient’s abdomen. The doctor will then push on that spot while looking at the image of the inside of the stomach projected by the endoscope. If he or she can see that the stomach wall is compressed with that motion, the doctor knows this is where the tube should be placed.

Once this site is identified, under local anesthesia, the doctor makes a small (1 cm) incision. The tube is then pulled through the stomach and out the abdominal wall. The tube is held in place on the inside by a plastic bolster or a water-filled balloon bolster, and on the outside by a plastic disk that sits on the surface of the abdomen.

Gastro-jejunostomy Tube

A gastro-jejunostomy tube refers to a gastrostomy tube with an extension that goes into the small bowel. When placed endoscopically, it is called a PEG-J tube or a JET-PEG, which stands for “jejunal extension through a PEG.” A PEG-J is put in by placing a standard PEG tube (as described above), and then inserting a smaller-caliber tube through the PEG. An instrument is then advanced through a channel in the endoscope, and the doctor will use it to grasp the inner tube and carry it into the small bowel with the endoscope. The doctor then releases the inner tube and carefully withdraws the endoscope, leaving the tube in place.

Jejunostomy Tube

A jejunostomy tube (J-tube) is a tube that is inserted directly into the jejunum, which is a portion of the small intestine. The endoscopic approach to placement is similar to the one used for the PEG tube. The only difference is that the doctor uses a longer endoscope to enter into the small intestine. Once the endoscope is in the small intestine, the doctor will once again look for the light shining onto the surface of the abdominal wall and look for the indentation into the small intestine wall when he or she presses externally on that spot. The doctor will cleanse and numb the skin, make an incision, and pass the tube through.

When to Use a Post-Pyloric Tube

A post-pyloric tube should be considered when there is a contraindication to placing the tube directly into the stomach. Patients with slow stomach emptying due to impaired motility (“gastroparesis”) should also be considered for a post-pyloric tube since they cannot tolerate infusion of feeds into the stomach without experiencing significant discomfort, reflux, or early satiety. Similarly, if the stomach outlet is narrowed or mechanically

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blocked, feeding into the intestine beyond the stomach becomes necessary.

A J-tube can prevent aspiration of tube feeds in patients who have delayed gastric emptying. Importantly, J-tubes do not protect a patient from aspiration of oral secretions. This form of aspiration is common in the elderly and patients with a weak swallow mechanism or impaired mental status.

PEG-J or JET-PEG versus PEJ

The decision to use a gastrostomy tube with small bowel extension tube (PEG-J or JET-PEG) versus a tube that goes directly into the small bowel (a PEJ or surgical jejunostomy) is based on a variety of factors. The first consideration is whether the patient already has an existing PEG tube. Some patients with PEG tubes discover after the fact that they cannot tolerate feeds into the stomach and they need a post-pyloric tube. In such patients, it is possible to convert the PEG to a PEG-J and avoid placing a completely new tube at an alternative site on the abdominal wall (which would also require a new incision).

A second consideration is whether a patient requires a tube in both the stomach and the small intestine. This scenario is common for patients with severe gastroparesis, who need a tube in the stomach to drain gastric juice that can build up and cause vomiting, and a tube in the small intestine for delivery of feeds. In such a patient, specially designed PEG-J systems that have an opening in the stomach portion of the tube and a second opening in the small bowel portion of the tube can be used to meet this dual function. Alternatively, these patients can undergo placement of two separate tubes, a PEG and a PEJ.

Other factors that should be considered when deciding between a PEG-J and PEJ are ease of placement and associated morbidity. PEG-J tubes can be challenging to place and maintain because the small bowel extension can either fall back into the stomach or become clogged due to its small caliber. On account of these problems, repeat procedures to reposition or replace the extension tube are common.

Tube Dislodgement

Tube dislodgement can occur when there is a traumatic tug on the tube or if the bolster holding the tube inside the stomach or

intestine has degraded. If the tube has been present for four or more weeks, a mature tract or lining has probably formed between the stomach and the abdominal wall. This means that the stomach (at the site of the tube) has adhered to the internal abdominal wall and will remain so even if the tube is removed. This adherence seals the hole in the stomach, preventing gastric contents from leaking into the abdominal cavity. It also keeps the opening in the stomach in a fixed location so a new tube can be easily placed into the tract at the bedside. In this case, tube replacement should be done as soon as possible, since the opening in the stomach or small bowel can close within twenty-four hours of tube dislodgement.

If a PEG tube has been in place for less than four weeks and the stomach has not adhered to the abdominal wall, the stomach will fall away from the wall when the tube is removed, leaving the hole in the stomach uncovered, leaving the patient at risk for leakage into the abdominal cavity and associated infection. Further, a new tube cannot be safely passed back through the abdominal incision and into the stomach if the stomach hasn't adhered to the wall, resulting in the tube sitting in the abdominal cavity rather than in the stomach. In this instance a surgical intervention may be necessary.

Low-Profile Devices

If a patient requires a long-term PEG or PEJ, he or she may be a candidate for a low-profile device ("gastrostomy button") when it is time to replace the first tube, usually two to three months later (after the tract has matured). Unlike the standard G- or J-tube, the low-profile device rests flat on the skin surface. The user connects extension tubing to the low-profile device during feeds. The device consists of a short tube (1 to 5 cm) with an inflatable balloon or a "mushroom" bolster on one end (inside the stomach or intestine) and a capped feeding port on the other end.

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Editors Note: Lauren Schwartz, MD practices general gastroenterology with a focus on disorders of intestinal malabsorption, intestinal failure, and nutrition support. She is currently

an Assistant Professor of Medicine with dual appointments in the Division of Gastroenterology and the Recanati Miller Transplantation Institute at Mount Sinai Hospital. In the latter role, Dr. Schwartz serves as the gastroenterologist for the Intestinal Rehabilitation and Transplant team.

Dr. Schwartz's expertise includes management of short bowel syndrome, celiac disease, inflammatory bowel disease (Crohn's disease, ulcerative colitis), and chronic intestinal pseudo-obstruction. On the research front, Dr. Schwartz has been involved in clinical trials examining the effects of Gattex, a GLP 2 hormonal analog, on intestinal absorption and PN weaning.

Nutrition and You -

Increasing Calories in the Enteral Diet
*Brittany L. Wright, RD, Enteral Specialist,
Coram CVS/Specialty Infusion Services*

Weight gain and subsequent maintenance are common concerns for the enteral, or tube-fed, patient. Working with your dietitian and physician, you can find ways to increase your caloric intake. Generally speaking, a weight gain of a half-pound to a full pound per week can be achieved with an increase of approximately 250–500 calories per day. When comparing the enteral diet to the oral diet, strategies for increasing calories are quite similar. These strategies include:

Increase the Volume

In an oral diet, you would first simply try eating more. The same idea applies to the enteral diet. If you use the bolus method for tube feeding, the most basic strategy to increase calories is to increase the volume of each bolus meal. Try slowly increasing a meal volume by 30- to 60-mL (1- to 2-ounce) increments. Often, the adult stomach can tolerate a total volume of 240–480 mL per meal. If you are receiving a continuous feed via pump, a slow increase in rate (start with increments of 2–5 mL/hour, as tolerated) can be used to obtain a goal of an additional 120–480 mL per day.

Increase the Frequency

If unable to tolerate additional volume per bolus feeding, you can try increasing the number of feedings per day. Again, an increase of 120–480 mL per day is a practical goal. This can be accomplished by adding an additional meal per day (space meals at least two hours apart). Or, you can add two to three smaller, 60- to 120-mL "snacks" between normally scheduled bolus feedings, or add one smaller feeding at bedtime.

FEEDING TUBES continued on page 4

“Like” SPOHNC on Facebook

FEEDING TUBES continued from page 3**Increase the Density**

In terms of food, it is understood that a bite of cheesecake packs more calories than the same amount of fruit does. This concept also applies to various enteral formulas. If an increase in formula volume or frequency is not tolerated, the next strategy is to manipulate the formula density.

Calorie density is noted in the name of most commercial formulas. A “1.0” formula provides one calorie per milliliter. Try increasing the formula density incrementally, using formulas that provide 1.2, 1.5, and 2.0 cal/mL. (Note: High-density formulas contain less water than low-density formulas. If switching to a denser formula, additional water will have to be provided as flush. Consult the formula label to compare total water content in each product. A registered dietitian can help you determine your total fluid needs.)

If using a blenderized formula, you can increase the density by mixing the formula with less water. A variety of products can also be added to enhance nutrition without substantially altering volume. These include powdered products such as a protein module or a liquid MCT (medium-chain-triglyceride) oil. MCT oil is more readily digested than other forms of fat, making it a good choice for those struggling with diarrhea and malabsorption.

Keep in mind that not all interventions are appropriate for every patient. Be sure to talk to your doctor before making any changes to the enteral regimen that has been prescribed for you. Working with your doctor and dietitian to formulate an individualized, balanced approach for increasing calories is the best way to go!

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Home Tube Feeding With Blenderized Foods

*Theresa A. Fessler, MS, RDN, CNSC -
University of Virginia Health System*

Think about the wide variety of foods most people eat every day. Now imagine “eating” these same foods using your feeding tube. With today’s high-performance blenders this is possible, and many home enteral nutrition (HEN) consumers and caregivers

are using blenderized foods instead of, or as a supplement to, standard canned enteral nutrition (EN) products.

There are several reasons some HEN consumers use blenderized foods. Some have allergy or intolerance to certain ingredients that are present in most standard EN products, such as corn, cow’s milk, or soy proteins. Others desire more variety, and/or healthy, unprocessed natural foods for a diet lower in sugar and with phytonutrients and fibers. Most conventional EN formulas contain corn syrup, maltodextrins, sugar, soy, corn oils, and casein and soy proteins. While they provide all the known essential vitamins, minerals, and protein, they often do not provide the wide variety of phytonutrients and fibers present in natural foods.

Homemade blenderized foods can be less expensive than commercial products, which is an important factor when insurance does not cover EN formulas. Some who are concerned about the environment like blenderized foods because there are fewer cans and cartons to throw out. Many HEN consumers enjoy sharing meals with their families and experiencing the sight and smell of foods while they prepare and use blenderized meals.

Choosing and Preparing Food

Blenderizing foods is easier than you might think and many foods can be used. High-speed and commercial-quality blenders such as Vitamix® or Blendtec™ work best for more complete liquefaction of foods. Foods should be cut into chunks and placed in a blender along with enough liquid to allow blending to a smooth consistency. You may need to strain the blend to remove small chunks or seeds.

Foods that are popular for blending include sweet potatoes, bananas, quinoa, avocado, oats, nut and seed butters, chicken, yogurt, kefir, various grains, and milk (cow’s, soy, almond, coconut, etc). Other liquids include water, broths, and juices. Some foods have more potential to clog tubes, such as string beans, blueberries, and flaxseeds. Eggs can become lumpy if not thoroughly cooked prior to blending. Brown rice, fruits, vegetables, lentils, toasted breads, and crackers work well for blending, and olives, white pasta, white rice, breads, muffins, and bagels tend to gum up

in the blender.

General food safety principles are very important, especially if the person using tube feeding has compromised immune function. As with any food preparation, hand washing is essential, and fresh vegetables and fruits and dried legumes should be carefully cleaned to remove any soil, microorganisms, and other contaminants. Dried legumes should be inspected for small pebbles prior to cooking.

Raw foods can be used, but foods that normally require cooking (such as meats, brown rice, potatoes) should be cooked just as they would if they were being eaten by mouth. Blenders and syringes need to be thoroughly cleaned right after each use. Unused blends should be promptly covered, refrigerated and consumed within twenty-four hours.

Feeding the Blenderized Formula

Blenderized foods can be administered the same ways as regular canned formula—by gravity, bolus, or pump. However, most often they are infused into G-tubes (including PEG-tubes and low-profile devices) slowly with a 60 mL syringe, by using gentle pressure on the syringe plunger (called bolus feeding). All methods work well with tube diameter of 14 French size or larger. Although very uncommon, some people use nasogastric (NG-) tubes in the home setting; using blenderized food is difficult or not possible with small-bore NG-tubes.

Although it is less common, some people with G- or J- (jejunal) feeding tubes administer their blends with feeding bags and a pump. This will typically only work with thinner blends, which usually requires more fluid be added to the mixture and thus would not be appropriate for those with fluid restrictions or high calorie needs.

With pump feeding, the blend should be infused within two hours to avoid spoilage. If the blend is left in feeding bags too long, ingredients may separate out in layers, increasing risk for clogging and inconsistent intake of nutrients. Some manufacturers of feeding pumps have specifically stated that their pumps are not to be used with anything but commercial formula.

Creating Healthy, Balanced Meals

Many blenderized diet recipes are available, but consultation with a registered dietitian/

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nutritionist (RD/RDN) is crucial to ensure that a diet is appropriate for an individual's specific nutrition needs; otherwise, one is at risk of under- or overdosing on various nutrients. RDs will calculate calorie, protein, water, and micronutrient needs based on age, height, gender, laboratory information, medical diagnoses, post-surgical status (if applicable), activity levels, weight, and, for children, growth goals. RDs can evaluate food and fluid choices and monitor a person's nutritional progress.

Some people who have poor digestion or malabsorption will not be able to use blenderized foods. Others might need to restrict fiber. If you are transitioning from conventional canned EN formula to blended foods, it is recommended you try one new food for several days and monitor tolerance before adding another new food. However, if you were eating a variety of foods just prior to starting EN, this will not be necessary.

Use of blenderized feeding can range from adding one fruit or vegetable blend daily to a regimen of standard commercial EN formula, to a diet that consists only of blenderized foods. One way to make a balanced meal is to portion out foods in

amounts that would otherwise have been eaten by mouth, add liquid, and blenderize. Another way is to blend a specific number of portions each day from the different food groups: carbohydrates (grains and starchy vegetables), protein, vegetable, fruit, dairy (or dairy substitutes), and fats and oils.

Financial Coverage

For help with the expense of blenders, check out the manufacturers' Web sites or call the companies (for Vitamix, Blendtec, Oster®, and other brands of blenders); some reduce prices for those using the blenders for medical use. If you are just starting out with blenderized foods, it is wise to use a regular or less expensive blender at first, to make sure blenderized diets will work for you before purchasing a more expensive one.

Editors Note: The Oley Foundation was founded in 1983 by Dr. Lyn Howard and her patient, Clarence "Oley" Oldenburg, to enrich the lives of those living with home intravenous (parenteral) nutrition and home tube feeding (enteral nutrition) through education, advocacy, and peer to peer networking. The Oley Foundation website (www.oley.org) offers a wealth of information.

April Awareness Month Is Just Around the Corner!

Would you like to see yourself, or your chapter, featured in a future issue of News from SPOHNC?



April is Oral, Head and Neck Cancer Awareness Month. Last year, quite a few SPOHNC Chapters celebrated awareness with some very unique and creative events and ideas. Everything from Taste Events, to Exercise Classes, to Recognition Dinners, Bake Sales and Screenings were taking place throughout the month of April and beyond. Niagara Falls was even lit up in SPOHNC's colors!

Many of your events were featured in "News from SPOHNC," on the SPOHNC website and even on facebook. We want to promote you, while you promote Awareness, so think of a unique way to gather your community, and let us help you. We have materials to share, and will get you well on your way to a successful event. Contact SPOHNC at info@spohnc.org, or at 1-800-377-0928 for help. We have sample donation

letters, press releases and sample flyers that can be customized for you.

Would you like to hear from other Chapters, what has worked for them? We can also put you in touch with others who have held an event similar to what you'd like to host, or we can help you come up with an original idea of your own. Promoting awareness of oral, head and neck cancer is such an important task – and we are all part of the April Awareness Campaign, so let's work together.

Let us know what's happening, so we can promote your event on our facebook "group" and "page" and on our website. After your event, send us photos and a paragraph or two sharing how you raised awareness of oral, head and neck cancer. We'll publish it in our newsletter, and feature you and your group on our website.

How will you promote awareness this year? – with your Chapter, or in your Community? We're here for you – and we want to hear from you!

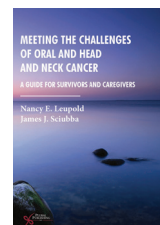
Need Someone To Talk To?

SPOHNC's patient match program - our National Survivor Volunteer Network - is here for you. If you'd like to speak with someone who survived and thrived after the same cancer diagnosis and treatment as you, call SPOHNC at 1-800-377-0928, x4 to find your match.

"SPOHNC has provided great information and support..."

~ Judy B.

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Great News!! We Have Walked In Your Shoes Is Back!

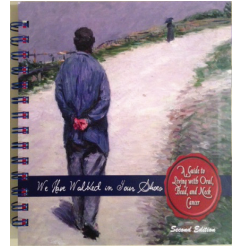
SPOHNC is very pleased to announce that the long-anticipated and updated version of ***We Have Walked in Your Shoes: A Guide to Living with Oral, Head and Neck Cancer Second Edition*** is now available!

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We Have Walked in Your Shoes: A Guide to Living with Oral, Head and Neck Cancer Second Edition is a welcomed guide for patients, survivors and their families. This resource contains the basics about the symptoms and diagnosis of head and neck cancer, types of treatment and common side effects. It also offers a section to list your healthcare team, a personal calendar and journal, diet and nutrition information, and a list of resources. It is a remarkable resource, beautifully illustrated with impressionistic paintings of the 1800s.

We Have Walked In Your Shoes... contains a wealth of information for newly diagnosed patients, caregivers, and those patients going through treatment. Healthcare professionals, clinics, diagnostic centers and cancer institutions throughout the U.S. will also find this book to be of great value for their patients.

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Fudge Truffle Cheesecake

(from Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges Volume 2)

Chocolate Crumb Crust:

1 1/2 c. vanilla wafer crumbs
1/2 c. powdered sugar
1/3 c. Hershey's cocoa
1/3 c. melted butter or margarine

In medium bowl, combine all ingredients and press firmly on bottom of 9 inch springform pan.

2 c. (12 oz pkg.) Hershey's semisweet chocolate chips
3 (8 oz) cream cheese, softened
1 (14 oz) can sweetened condensed milk (not evaporated)
4 eggs
2 tsp. vanilla extract

Heat oven to 300 degrees. Prepare chocolate crumb crust as above. Set aside. In a heavy saucepan, over very low heat, melt chips, stirring constantly. In a large mixing bowl, beat cheese until fluffy. Gradually beat in sweetened condensed milk until smooth. Add melted chips and remaining ingredients. Mix well. Pour into prepared pan. Bake one hour and five minutes until center is set. Cool. Chill. Refrigerate leftovers. Serves 14 to 16.



~ JoAnn Tripi, New York

A TIME FOR SHARING...A Very Special Gift

The Christmas of 2014 was very special for two people. So special that Aunt Su Su decided to have an interview with her niece, Katie, age 9, granddaughter of Nancy Leupold. Katie is a 4th grader and lives in Lexington, Massachusetts, with her parents, two older brothers and Oliver, the family dog. She recently participated in a neighborhood charity event and raised money for SPOHNC as a Christmas gift for her grandmother.

Su Su: *Katie, can you tell us about the neighborhood event you participated in to help raise money for SPOHNC.*

Katie: “Well, every year, my neighbor, Christina, has a fund raiser for kids who want to raise money for a charity, and you put up a table and put up a poster and jar for money and people can walk around and ask you questions and they see what charities they want to give money to and they put their donations in a jar.”



Su Su: *How did you decide to choose SPOHNC for your fundraising event?*

Katie: “Well, I was wondering what I should do for my grandmother’s Christmas present. I’ve known about SPOHNC for a while, but had never looked at the website. My mom showed me the SPOHNC website and I read more

about my grandmother and the work that SPOHNC does and I decided to help SPOHNC this year at the neighborhood charity fair.”

Su Su: *Tell us more about SPOHNC. What did you learn about SPOHNC when putting together the fundraiser?*

Katie: “My mom wrote down the letters for SPOHNC and what it stands for: Support for People with Oral, Head and Neck Cancer. Then I looked up the website and I found my grandmother’s story of how she started SPOHNC. It was extremely interesting how, when she was in the hospital, she wanted to start a support group for other people with head and neck cancer because it’s more visible than other cancers. I thought it was really nice how the doctors helped her start SPOHNC and how SPOHNC helps a bunch of people today.”

Su Su: *Can you tell us more about the day of the event and your booth?*

Katie: “On the day of the event, it was cold out and I was expecting almost nobody would come, but then I saw a huge group of people coming and everyone set up their tables and booths and it looked like it was bigger than last

year’s event. My booth was kind of like a puzzle: I had a poster that told you the letters for SPOHNC and then underneath the letters, there were words that went with the letters and you had to match them up. I was really proud because I wrote down on my poster “Founded by my grandmother, Nancy Leupold, in 1991”. I raised \$82.85 for SPOHNC that day.”

Su Su: *What was the best part of this experience for you?*

Katie: “Knowing that I was doing the right thing, raising money for my grandmother’s charity. It made me feel proud and made me feel excited thinking about my grandmother opening her Christmas present.”

Grandmother: “I had no idea of what could be in the wrapped shoebox that Katie excitedly handed me on Christmas morning. However, it was quite heavy and no matter what I guessed, I never imagined that the shoebox would contain a young child’s hard work raising money for SPOHNC. This was truly a very special Christmas gift to me from Katie.”



A Warm Welcome



SPOHNC is honored to welcome Eugene N. Myers, MD, as the newest member of our esteemed Board of Directors, the governing Board of SPOHNC. Dr. Myers is an internationally known head and neck surgeon; a leader in the treatment of head and neck cancer. He is a graduate of the University of Pennsylvania in 1954 and received a Bachelor of Science in Economics. He earned his Doctor of Medicine degree in 1960 from Temple University. He then did a residency in Otolaryngology at Massachusetts Eye and Ear Infirmary. He served as an Otolaryngologist in the 97th General Hospital in Frankfurt, Germany from 1965-67. He returned to his home town of Philadelphia and for four years was on the faculty of the University of Pennsylvania. In 1972, Dr. Myers was recruited to the University of Pittsburgh as Chairman of the Department of Otolaryngology and served in this role for 33 years.

He is the author or co-author of the leading texts in the field of head and neck cancer, and has been President of many of the important organizations in our specialty including The American Society for Head and Neck Surgery, The American Academy of Otolaryngology—Head and Neck Surgery and The American Board of Otolaryngology.

Dr. Myers has been a good friend to SPOHNC for more than 15 years, contributing his time and expertise reviewing many of SPOHNC’s publications and resources. We welcome Dr. Myers to our Board, and we wish to thank him for accepting our invitation to serve alongside the dedicated individuals who have assisted SPOHNC in fulfilling our mission for more than twenty years.

Connect with SPOHNC’s “group” on Facebook

My Feeding Tube Experience

I have had a G-tube since October 2013 and it was something I was very reluctant to do because I was "MR. MACHO" and I was only 67 - way too young to have a feeding tube, since I thought only 80-90 year old people on their deathbeds in nursing homes had feeding tubes. After having tongue and



throat cancer back in 2005 and enduring seven weeks of radiation treatments twice each day along with three chemotherapy sessions, I was declared cancer free and

everything was fine for a few years until I started developing a numbness in my lower lip and tongue. My throat doctor thought I might have had a minor stroke so he ordered tests and it was determined that I had nerve damage from the radiation.

My ability to swallow was also diminishing as it began to take me longer and longer to complete a meal so my doctor referred me to the local medical school for evaluation and therapy. I was given a swallowing test in January of 2013 and failed it, so after a few more months of therapy, I was given a second swallowing test in May and I failed it so miserably that they stopped the test after just a few minutes as I was aspirating so badly. They still could not convince "MR. MACHO" that he needed a feeding tube so I continued on through the summer eating more and more slowly and coughing and gagging for an hour or so after each meal. Finally, in September 2013, "MR. MACHO" came to his senses and I told my doctor I was ready to get a feeding tube, so in October, my life made a definite change for the better. The day after I got my G-tube I was a new person and told my son, who is a Paramedic, that I should have had a G-tube put in a year or two before as it made my life so much more tolerable. No more choking and coughing! Wow, that is a great feeling.

I am sitting at our breakfast bar right

now as I type this and I am hooked up to my feeding tube having my breakfast. I have always been a do-it-yourselfer so I took an old microphone stand and adapted it so it will hold my 5 oz. syringe which I use while I gravity feed via a 12" long Bolus connector tube that I connect to my feeding tube. We still travel some so I made a syringe holder for use in our car and I also made an attachment for it to hold my syringe while feeding in a motel room. I have limited ability to lift my arms above my head for long periods of time due to the radiation damage also.

Does a feeding tube change your lifestyle? Yes, it changes it as much as you allow it to change it. My wife and I still go out to eat with friends but I just tube-feed before we leave home and I go along to enjoy the social interaction. All of our friends know that I am a tube feeder so it is not a problem. I even try to have a little fun with my inability to eat. A friend and fellow tube-feeder who I met through the Oley forum told me a few things he has tried at restaurants and I have enjoyed using them to lighten up the situation at restaurants as well. Just a few days ago my wife and I went to a steak restaurant with about a dozen friends and as the waitress was taking everyone's orders she got my wife's order for a nice steak and turned to me and politely said "and Sir, what would you like to order?" I put on my "sad" eyes and looked up at the waitress and said "Mam, we can only afford for one of us to eat tonight and tonight is my wife's night to eat." You should have seen the look on the waitress' face! Of course I quickly told her why I would not be ordering and she got a good laugh about the trick as did all of our friends. I have found that putting a little levity into the situation makes being a tube-feeder much more tolerable.

There have even been a few situations where we have been on road trips with friends and have "eaten" in restaurants that were not crowded, where we were able to get a corner booth so I would tube feed right in the restaurant. Whenever I do this I go in the restroom and hook up my Bolus connector tube and syringe and close the shutoff valve and just leave it all inside my suit until I sit down at the table with my back towards the serving area so only my friends

can see my tube. This has worked well with no problems as the world we live in is now much different. When I was younger I could not imagine a mother breast-feeding her baby in public, but now that mothers breast-feeding their infants in public is widely accepted, I can't see any difference in us tube-feeding in public, as long as we are discreet about it.

My first tube pulled out of my stomach about four months after I got it. Being a newbie, I went to my doctor and she was not there, so I was sent to the ER to have it replaced. Six months later the balloon on tube #2 broke as I was outside washing the house and the whole tube came out. It was late on a Friday so I told my wife that I wasn't going to the ER on a Friday night to sit there all night with all the Friday night drunks, shooting victims, etc., so I removed the remnants of the broken balloon, washed my old tube thoroughly and put a dab of KY jelly on my stoma and on the end of the feeding tube and simply reinserted the old tube myself and taped it to my belly so it would not fall back out since it had no balloon. The next morning I called the home health care duty nurse and she brought me a new tube and she allowed me to remove and replace it myself. I now have an extra feeding tube which I carry with me any time we travel in case I have to change it again due to a broken balloon.

I carry a complete feeding kit in my car trunk at all times as you never know when you might be away from the house when a meal time arrives. I use a small black leather bag about the size of a woman's make-up bag to carry my syringe, bolus connector, 2 or 4 cartons of formula, a bottle of water, and my cleaning brushes, etc. I used it just the day before yesterday in the car while my wife was in the beauty shop.

In closing I will say that having a G-tube is not really a big problem for me and the biggest regret that I have is waiting soooooo long to take my doctor's advice to get one. If your doctor tells you to get a tube, I strongly recommend that you listen to him and do not be stubborn like I was. I can assure you that you too will be saying "Why didn't I do this sooner?"

~ Sanford in Saraland, Alabama
flachusnret@comcast.net

HEAD AND NECK CANCER NEWS

Oral Human Papillomavirus Infection More Likely to Persist in Older Men

PHILADELPHIA - Jan. 9, 2015 - Oral infection with human papillomavirus 16 (HPV16), which is the type of HPV most frequently linked to HPV-driven head and neck cancers, was more likely to persist 12 or more months in men older than 45 than in those younger than 45, according to a study published in *Cancer Prevention Research*, a journal of the American Association for Cancer Research.

"Oral HPV16 is the HPV type most commonly found in HPV-driven oropharyngeal cancers, which have been increasing in incidence recently in the United States," said Christine M. Pierce Campbell, PhD, MPH, an assistant member in the Department of Cancer Epidemiology and Center for Infection Research in Cancer at the Moffitt Cancer Center in Tampa, Florida. "We don't know how long oral HPV infection must persist to increase risk for head and neck cancer, but we assume it would be similar to cervical infection, where it is generally believed that infections persisting beyond two years greatly increase the risk of developing cervical cancer."

"Our results show that some oral HPV16 infections persist in men for four years or more and that persistence seemed to increase with age," continued Pierce Campbell. "Genital HPV infections are generally cleared within two years, so our data show that oral infections may be more likely to persist than genital infections."

"Unfortunately, there are currently no methods to detect precancerous lesions of the head and neck," Pierce Campbell added. "So, before our data can be translated for patient benefit, we need more studies of HPV-related head and neck cancers to develop screening methods that may be useful in a clinical setting."

Pierce Campbell and colleagues analyzed oral samples from 1,626 men participating in the HPV Infection in Men (HIM) Study, an ongoing, multi-national cohort study of the natural history of HPV infections in men. Oral samples were collected at enrollment and then every six months for up to four years.

Over the course of the study, HPV16

was detected in two or more oral samples from 23 men. For 10 men, it was present in the sample collected at enrollment. Infections present at the start of a study are called prevalent infections while those that arise during the study are called incident infections.

Among the 10 prevalent infections, nine lasted one year or longer, eight lasted two years or longer, and two lasted for four years or longer. Among the 13 incident infections, four lasted one year or longer, one lasted two years or longer, and none lasted three or more years.

The proportion of incident infections persisting for one year or longer increased with age. All incident infections among men older than 45 persisted for one year or longer, 50 percent of those infections among men ages 31 to 44 persisted for one year or longer, and none of the incident infections detected among men ages 18 to 31 persisted for one year.

"Our observation that prevalent oral HPV infections persisted longer than incident infections is consistent with what has been seen for cervical and anal HPV infections," said Pierce Campbell. "Prevalent infections are likely to have been present for a while, increasing the likelihood that they will be persistent."

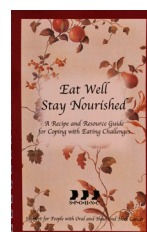
Funding for the study was provided by Merck Sharp & Dohme, the American Cancer Society, and the National Cancer Institute Intramural Research Program. The infrastructure of the HIM Study cohort was supported through a grant from the National Cancer Institute. Pierce Campbell declares no conflicts of interest.



*"The best and most beautiful things
in the world cannot be seen or even
touched. They must be felt
with the heart."*

~Helen Keller

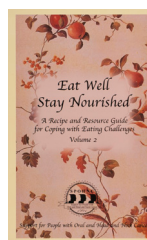
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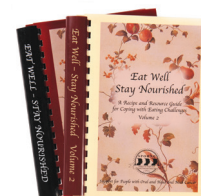
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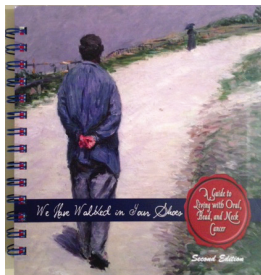
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