

# Secure Start™

# eNewsletter

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*The Healing Circle*



## FEATURE STORY

# The Healing Circle

**Friends of Ostomates Worldwide–USA circles the globe with supplies and hope**

*Imagine living with an ostomy in a developing country and having to use plastic bags, metal cans, rubber gloves, rags or towels to manage your ostomy. Unfortunately, this situation is the reality for millions of people.*

Thanks to Friends of Ostomates Worldwide–USA (FOW-USA), this reality is changing. Ann Favreau, President of FOW-USA, knows that, as a new or experienced person with an ostomy, your pouching system requirements vary from time to time. Because of these changes, you may have unused supplies. She implores you, “Don’t throw them away! Needy people who have no access to supplies or can’t afford them will benefit from your donated products through the efforts of FOW-USA.”

*(continued on the next page)*



**FOW-USA sends donations to over 70 countries where people have no access to supplies.**

## FEATURE STORY

## The Healing Circle

(continued)



**Product donors send supplies to the FOW-USA warehouse space in Louisville, KY where volunteers can unpack, organize and match the donations with recipients' needs.**



**Volunteers pack supplies for shipment to those who have requested assistance and load the supplies onto large pallets for shipping.**

FOW-USA is a non-profit organization, established in 1986, that accepts unused ostomy supplies and ships them overseas to areas where they are needed. Through their newsletter, Facebook, website ([fowusa.org](http://fowusa.org)) and board members' appearances at local, regional, and national conferences, FOW-USA is telling their story and gaining support for their global efforts to make a difference in the lives of people with ostomies.

In 2016 alone, FOW-USA has sent 93 shipments to individuals and groups in over 70 countries. They accept pouches, skin barriers, skin wipes, paste, tapes, belts, pouch covers, scissors and pediatric supplies. Their volunteer warehouse staff unpacks, inspects, and then repacks the supplies according to the recipients' requests. The warehouse coordinator works with shipping companies to send the products.

FOW-USA also has an educational component to its mission. This year they are supporting the efforts of doctors Carlo Pezcoller and Harikesh Buch in the *Lions for Stoma Care Project* to train nurses from developing countries in the care of people with ostomies.

Emails of gratitude flood in daily from all corners of the world. An enterostomal therapy nurse (ET) from Nepal wrote about a 13-year-old girl with an ileostomy whose remote home was damaged in the recent earthquakes. She was unable to attend school because of lack of proper supplies, but thanks to FOW-USA, she is back in class and doing well.

"Every time I speak to a local ostomy group, it's always the stories that move people to action," says Ann. "Being involved in this organization is a wonderful way to give back to the world."

Visit FOW-USA on **Facebook** or **[fowusa.org](http://fowusa.org)** to learn more, sign up for their newsletter or make an online donation.

*(continued on the next page)*

## FEATURE STORY

## The Healing Circle

*(continued)***How to donate to FOW-USA**

Simply take the unused supplies out of their original boxes, tear off the portion that includes the description, place everything in a plastic bag, and then mail in a basic shipping envelope. This process will save space and lessen the cost of shipping. Send unused supplies to:

**FOW-USA**  
**4018 Bishop Lane**  
**Louisville, KY 40218-4539**

FOW-USA will respond with a letter of receipt that can be used for tax purposes. Your shipping costs are also deductible. If you would like to send a monetary donation to help cover overseas shipping fees, please use the same address.

A selection from  
*It's Okay To Have An Ostomy*

### The Healing Circle by Ann Favreau

Caring people  
 Conquer affliction  
 Move as survivors  
 To comfort others.

Listening ears  
 Empathetic hearts  
 Hands outreached  
 To make a difference.

Touching others  
 Links of care  
 Connect us all  
 In the Healing Circle.

## It's Okay To Have An Ostomy

by Ann Favreau

### A poetic journey of inspiration, support and revelations

When Ann Favreau received a sigmoid colostomy due to colorectal cancer in 1988, little did she know that it would significantly contribute to a wonderful new journey. She joined her local ostomy support group and was encouraged by a professor, who was also a member, to deal with her pain and despair through writing.

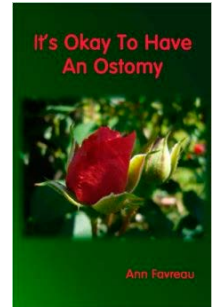
Ann chose the genre of poetry, and her current 40-page book *It's Okay To Have An Ostomy* is a testimony to the power of self-expression. She used each colorful experience she encountered as an ostomate and leader in the former UOA and the International Ostomy Association (IOA) as fodder for her beautiful poems.

Snippets of Ann's story are paired with original poems which cast cancer cells as bullies, hope as a yellow balloon and caring people as the healing circle. Her images are vivid and shoot straight to the heart.

One reader wrote on The Blue Hope Nation Facebook page, "I received the book, '*It's Okay To Have An Ostomy*' last night. It was very inspirational. I am feeling overwhelmed by this diagnosis and I am trying to maintain an outlook that is positive. Yesterday was an emotionally tough day and the book helped me move from a place of despair."

Whether you have had your ostomy for years or are just getting used to living with one, *It's Okay To Have An Ostomy* belongs on your bedside table, desk or anywhere you need inspiration.

Order *It's Okay To Have An Ostomy* at [Amazon.com](https://www.amazon.com). Proceeds are donated to FOW-USA.





NEWS FROM HOLLISTER

# Secure Start Corner

Meet the smile behind the voice



## Natali

**Region:** East Coast  
**Title:** Lifetime Service Coordinator, Ostomy Care  
**Length of Service:** 2 Years

**All-Time Favorite Movies:** I enjoy all of the Harry Potter movies (but the books are better), A Knight's Tale, and the first two Mummy movies.

**Can't live without:** Coffee. SO MUCH COFFEE.

**What is your favorite flower and why?** I love sunflowers. They make me think of summer.



## Ryan

**Region:** Midwest  
**Title:** Acute Care Coordinator, Ostomy Care  
**Length of Service:** 2.5 years

**All-Time Favorite Movies:** My faves include The Italian Job, Gone in 60 Seconds and Tomorrow Never Dies.

**Can't live without:** My golf clubs.

**Special talent:** I love to bake custom cakes from scratch.

*(continued on the next page)*

NEWS FROM HOLLISTER

## Secure Start Corner

(continued)



### Megan

**Region:** Entire U.S.  
**Title:** Secure Start Service Coordinator, Continence Care  
**Length of Service:** 8 months

**All-Time Favorite Movies:** A League of Their Own and The Blind Side are my favorites.

**Can't live without:** My daughter Charlotte and coffee.

**Special talent:** I have mastered the headstand.

**What is your favorite flower and why?** Peonies – because they are beautiful and delicate.



### Alfredo

**Region:** West Coast  
**Title:** Lifetime Service Coordinator, Ostomy Care  
**Length of Service:** 4.5 Years

**All-Time Favorite Movies:** I would have to say Home Alone 1 & 2 and Gladiator.

**Can't live without:** BBQ and my cell phone.

**Special talent:** I customize cars and motorcycles.

**What is your favorite flower and why?** Roses, because they're the best way to show love to your spouse.



## ASK THE EXPERT

# We've Come a Long Way

## A look at ostomy pouching systems from a historical perspective

by Thom R. Nichols,  
Research Fellow: Biostatistics and Health Economics, Hollister Incorporated

In 2016, people with ostomies have a variety of pouching systems to choose from, but this certainly was not the case in the past. Let's take a look at how the pouching system has evolved through the years.

The year is 1706 and historical records recount a battlefield wound resulting in a prolapsed colostomy. This instance, perhaps, is the first stoma ever recorded. In a mid-1700s surgical textbook there is an etching of a woman looking down at her abdomen. She has a colostomy and in her lap are rags and moss to absorb the output of the stoma. Then, in 1776, there is a record of a French physician constructing a stoma due to intestinal blockage. A sponge held tightly to the abdomen by an elastic band absorbed the output. While stoma construction was rare at this time, there are other reports of stoma formations, and of stoma output being managed through a variety of mechanisms such as leather pouches with drawstrings. Along with regular stoma enemas, these are the first records of attempts at creating ostomy appliances.

*“In the 1950s, innovation in products, patient care and surgical techniques evolved.”*

In 1912, Mary Manney, of Chicago, Illinois, filed a patent (granted in 1913) for a “surgical appliance, which may be secured to the body of a person upon whom a surgical operation has been performed; the device being particularly useful in operations of that character in which an incision has been made in the abdominal wall of the patient”. **See Figure 1.** In the 1920s, Dr. Alfred Strauss, a Chicago physician, came up with the idea of a rubber pouch that could be held in place on the abdomen by adhesives and belts.

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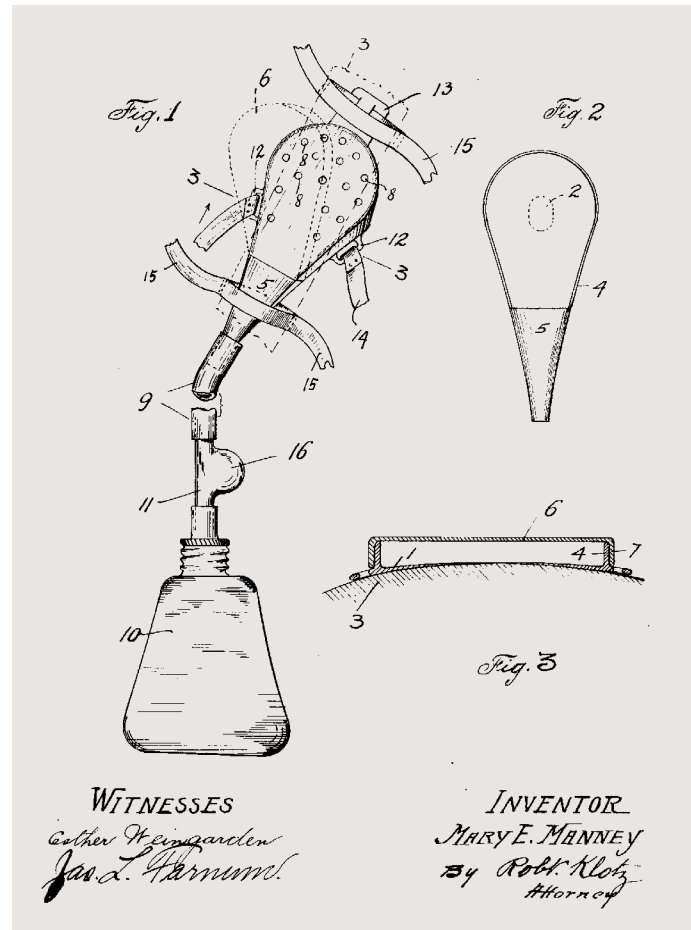
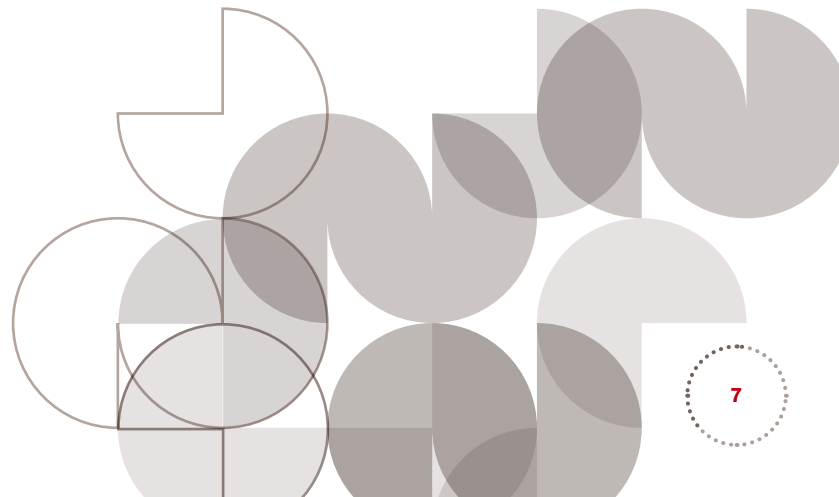


Figure 1



## ASK THE EXPERT

## We've Come a Long Way

(continued)

Numerous other ostomy appliance patents were to be filed in the coming decades.

In the 1950s, innovation in products, patient care and surgical techniques evolved. This decade would provide the roots for a new healthcare profession; that of the Enterostomal Therapist, created by a tenacious ostomate from Ohio by the name of Norma Gill. At the same time, developments in surgical techniques were being explored at the Cleveland Clinic by Dr. Rupert Turnbull and Dr. George Crile, and plastics began to make their way into the manufacturing process. However, many of the manufacturers of ostomy appliances continued to use heavy rubber pouches and rubber or plastic face plates developed in the previous decades.

By the 1960s, there were approximately 25 manufacturers of ostomy products in the U.S. The '60s saw progressive manufacturers of ostomy appliances turning away from bulky rubber bags to more aesthetic plastic films. This decade introduced Karaya, a major discovery in ostomy care. Karaya, originally a denture adhesive, is a vegetable gum produced as an exudate from trees of the genus *Sterculia*. As the story goes, Dr. Rupert Turnbull, while cleaning out a colleague's lab, accidentally spilled some Karaya denture powder on

his wet hands. He noticed that the Karaya had the ability to swell and cling to his wet skin and linked this to the needs of his ileostomy patients. In the 1960s, Karaya became the standard of use as a skin adhesive and protective barrier until the introduction of synthetic hydrocolloid barriers.

In the early '70s the ostomy industry began to explore the needs of the ostomate. The philosophy changed from "we can provide what you need" to "what do you need that we can provide?" Developers recognized that a pouching system must be more than safe and effective; it must also consider quality of life.

The pouching system we know today is a disposable product made of a skin-friendly, water-repellent, cloth-like material covering film laminates. Qualities include pouch films that help mask odor; noise-reducing pouch material; filters to help reduce ballooning of the pouch due to gas; flexible and thin skin barriers that are designed to stick to the skin with or without the use of belts; and integrated closures eliminating the need for separate clamps. All this is contained within a system that may weigh between 12 and 20 grams. Modern systems are low in profile, and designed for comfort, confidence and discretion; with a goal to get people with ostomies back into everyday life. And the rest is history.

**1912**

Mary Manney files a patent for the first ostomy pouch of its kind

**1960**

Plastic films become the standard for ostomy bags and Karaya is discovered as a skin adhesive and barrier

**1950**

Enterostomal Therapist job created and plastics begin to be used in ostomy appliances

**1970**

Advancements in ostomy care begin to improve quality of life for patients



## EVENT UPDATES

# Plan Ahead

## Mark your calendar for activity, support and fun

### Youth Rally 2016

July 25–30

University of Seattle, Washington

Youth Rally is a life-changing summer camp that provides a non-threatening environment for young people ages 11 to 17 with any sort of bowel or bladder dysfunction. Its ultimate goal is to encourage self-confidence and independent living. Many counselors were once campers and become invaluable role models for the young campers. Activities include motivational speakers, physical activities, educational sessions, field trips, a fashion/talent show and more. Plans are underway now for this year's Youth Rally. Go to [youthrally.org](http://youthrally.org) for more information.

### Girls With Guts Retreat

September 30–October 3

Stroudsburg, Pennsylvania

The Girls With Guts 2016 Retreat is a weekend-long event providing opportunities for women ages 18+ with Inflammatory Bowel Disease (IBD) and/or ostomies to foster friendships and learn ways to improve their lives emotionally, mentally and physically. The main focus is to help women create an in-person support network and find a “sister” that they will bond with and ideally maintain that relationship until the next retreat. Activities include presenters and participant-led groups. For more information and to sign up go to [Girlswithguts.org](http://Girlswithguts.org).

### Run for Resilience Ostomy 5K Events

October 1: Durham, North Carolina

October 1: Portland, Oregon

October 8: Boise, Idaho

October 15: Birmingham, Alabama

**Date to be Announced: London, England**

The WannaWearOne Ostomy AWEARness 5K is now the Run for Resilience! Initially launched by two dedicated WOC nurses in Durham, North Carolina as the WannaWearOne 5K, this event drew nearly 300 runners in 2015 in honor of Ostomy Awareness Day. The ultimate goal of the races is to educate, support and raise community awareness about people living with an ostomy. These family-friendly events have now grown from coast to coast and overseas. Though races will again take place in North Carolina and Oregon, 2016 will see new races in Idaho, Alabama and London, England! Interested in running the race but unable to physically attend the events? You can still sign up and run or walk your own virtual 5K race. Runners/walkers pay a registration fee and receive a T-shirt. Sponsorship support will offset event costs and all remaining proceeds benefit the United Ostomy Associations of America (UOAA). Go to [ostomy5K.org](http://ostomy5K.org) for more information and to sign up!

### Get Your Rear in Gear®

Multiple Dates

300 Events in 32 states

Walk, run, or ride in the largest colon cancer-focused event series in the country. It's a great way to become a part of the movement to prevent, treat and beat colon cancer. The Colon Cancer Coalition is celebrating the 12th year of Get Your Rear in Gear and has become a nationally recognized partner in the fight against colon cancer. Funds raised are reinvested in the local community to promote awareness, education, and screening. By the end of 2016, the Colon Cancer Coalition will have hosted nearly 300 run/walk and bike events in 32 states. Find an event in your community or create your own. Go to [coloncancercoalition.org](http://coloncancercoalition.org) for more information.



Youth Rally  
2015  
participants

## EVENT UPDATES

# The Ride Shifts Gears

## Get Your Guts in Gear announces a new format

Get Your Guts in Gear (GYGIG) is an independent, national, not-for-profit organization that raises awareness of Crohn's disease, ulcerative colitis and related conditions through multi-day cycling events that benefit and support inflammatory bowel disease (IBD) organizations and patient advocacy groups. Traditionally, GYGIG has held two rides in different parts of the country that connect both participants and volunteers at a deep level. Now they are taking a completely new route!

### Regional Rides:

This year, GYGIG will bring its multi-faceted community of riders, volunteers, friends, and family together for participant-led and participant-driven Regional Rides. Team captains will create these ride locations, dates, and details, while GYGIG will be there every step of the way to provide resources to create and execute each Regional Ride.

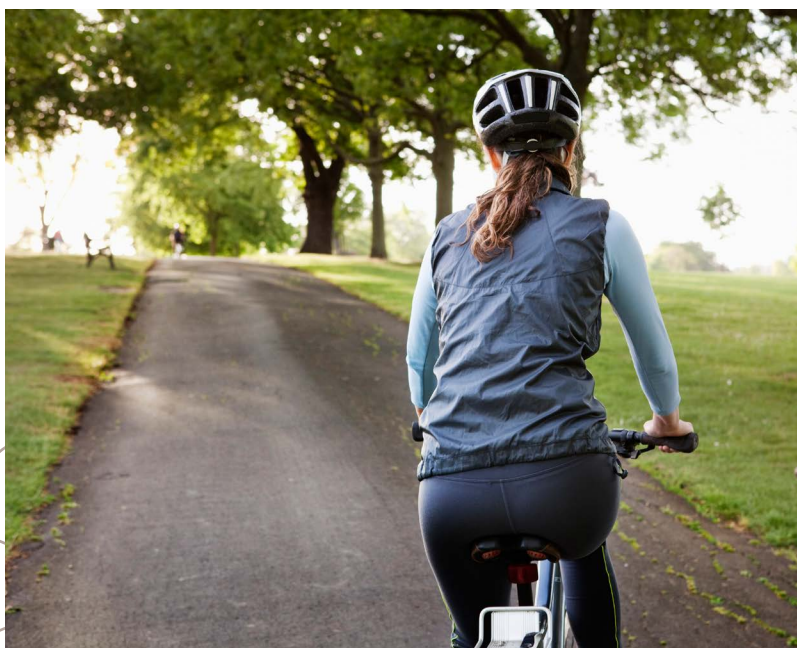
The ultimate goal of these Regional Rides will be to bring the GYGIG community together in more locations than ever before and to continue to grow and foster this community, while preparing for their exciting new adventure in 2017—Guts Across America!

### Guts Across America:

Guts Across America will have two components: Team Guts and Relay Ride Across America. Team Guts will be comprised of volunteers and riders who accept the challenge of biking across the country. Relay Ride Across America allows volunteers and riders to choose segments within the ride to join Team Guts and pass the baton to fellow riders and volunteers. More information, details and registration for Relay Ride Across America will be available soon.

Join the excitement! For more information and to view the Regional Rides that have been created so far, go to [igotguts.org](http://igotguts.org).

*Guts Across America – an exciting new adventure in 2017!*



## EVENT UPDATES

# Take Steps for Crohn's & Colitis™

## Get on your feet and join the fight

Do you know someone with Inflammatory Bowel Disease (IBD), or are you one of the 1.6 million Americans who battle it daily yourself? You have a chance to make a difference. Join a Take Steps walk today! They're sponsored by the Crohn's & Colitis Foundation of America (CCFA), and provide the perfect environment for you, your friends and family to connect and celebrate the steps that have been taken toward cures for IBD and also fundraise in support of mission-critical research and patient support programs.

Take Steps is a nationwide event in more than 120 communities across the country. You can walk as an individual or gather your friends, family, and co-workers to form a team. You'll have a blast! These walk events are filled with live music, food, kids' entertainment and educational materials.

Each year Take Steps chooses Honored Heroes who represent the Crohn's disease and ulcerative colitis warriors living in our community. One of this year's Honored Heroes is 12-year-old Sydni Jacobson who writes about her journey.

*"I want all of my friends and family to walk with me and I want to help raise money to find a cure for Crohn's ..."*



This year's Honored Hero, Sydni Jacobson.

Participants having fun at the 2015 Take Steps Event.



"In May 2014, I participated in the Take Steps Portland walk. It was a great experience and my family and I had a blast. I'm excited to be a part of the first Take Steps Walk in Eugene. I want all of my friends and family to walk with me and I want to help raise money to find a cure for Crohn's so other kids don't have to suffer."

The Take Steps website itself is a source of inspiration filled with videos, testimonials and photos of participants from individuals (like Sydni) to corporate teams. To get involved, **click here** to provide your state and ZIP code on the website and find a walk! It's that easy.

If you make a donation of \$25 or more, you'll receive a special thank you gift for personally supporting the CCFA mission. Become an Awareness Builder by fundraising \$100 or more and receive an exclusive 2016 Take Steps participant CURES T-shirt.

What are you waiting for? Go to [cctakesteps.org](http://cctakesteps.org) now.



COMMUNITY NEWS

# Ostomy United Goes the Extra Mile

## Triathletes team up for inspiration and support

The news is filled with inspiring stories of triathletes, but none is as inspirational as the story of Ostomy United—a whole team of triathletes with ostomies, their friends and supporters!

The team consists of those taking part as either triathletes or “Hooligans” (that cheer and support crew of Ostomy United). Members range in age from their teens to over 70 years old, and have participated in races from beginner triathlons to the Ironman 70.3-mile race.

Ostomy United was founded by Ted Vosk, a once homeless man who worked his way up to becoming a successful attorney in Seattle, while battling ulcerative colitis and Crohn’s disease. Within six months after an ileostomy he ran two half-marathons on back-to-back weekends for the Crohn’s & Colitis Foundation and got the idea for Ostomy United.

The team’s first official event was Washington’s Lake Meridian Triathlon in August 2015. Ostomy United won three medals that day, inspiring all in attendance and living up to the team’s motto, “There is nothing we can’t do!” Sponsor and donor support offsets costs of participation, with the remainder benefiting United Ostomy Associations of America and Youth Rally.

Secure Start services will be a Bronze sponsor of this year’s events. There are teams in Florida, Washington, Hawaii and Connecticut that travel throughout the country to compete in various triathlons. As part of their season this year, three teams will be competing in Half-Ironman triathlons (70-mile races) and two of those will be going on to compete in their very first full Ironman triathlons (140-mile races). Join a team today or show your support by visiting [Ostomyunited.org](http://Ostomyunited.org).



# Your Opinion Matters!

## Take our simple 60-second survey

We’re constantly looking for ways to improve the Secure Start newsletter, so we decided to go right to the source—our readers. Please take this 60-second survey and let us know which sections are most helpful to you and what we can add to make your life easier. After all, our goal is to offer solutions to make a difference in your life and in the lives of others in the ostomy community. This eNewsletter is one of those solutions—so make it your own.

Please click the link below to put change in motion...



**GO NOW!**

## WHAT'S SO FUNNY?

# What's So Funny?

## Brenda cooks up another batch of humor

### *Wheelchair Soup*

From Brenda's latest book: *Your Glasses Are on Top of Your Head*

For the last few years of my father's life, he was restricted to a wheelchair. Throughout his life, he was always creative when it came to cooking, spicing up meats for the grill or throwing some interesting soup together in the stockpot. That didn't change when he was bound to his wheelchair.

The only difference came when he cleaned out the refrigerator of the wilted veggies and some hunk of meat, the soup was always referred to now as wheelchair soup. After he peeled and cut everything, he'd add various spices into a big stockpot and, ultimately, it always tasted pretty good. One day I stopped over just as he was serving the "wheelchair soup." We were chatting away when I looked at my soup spoon and found a rubber band.

"Look what I found in my soup, Dad," I said, tilting my spoon forward so he could see the rubber band.

Without missing a beat, he said, "Well I didn't know how many were coming over; I had to find a way to stretch out the soup!"



**Brenda Elsagher**

Brenda Elsagher is an international speaker, author and comedian. Her books include: *If the Battle is Over, Why am I Still in Uniform?; I'd Like to Buy a Bowel Please!; Bedpan Banter; It's in the Bag and Under the Covers; and Your Glasses Are on Top of Your Head.*  
[livingandlaughing.com](http://livingandlaughing.com)

*Financial Disclosure: Brenda Elsagher received compensation from Hollister for her contribution to this eNewsletter.*

## Secure Start eNewsletter Resources

### Secure Start Services

1.888.808.7456

[www.securestartservices.com](http://www.securestartservices.com)

Secure Start Facebook Page 

### United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826

[info@uoaa.org](mailto:info@uoaa.org)

[www.ostomy.org](http://www.ostomy.org)

### Crohn's & Colitis Foundation of America, Inc. (CCFA)

1.800.932.2423

[www.ccfa.org](http://www.ccfa.org)

### Inspire.com

[www.inspire.com](http://www.inspire.com)

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## Share Your Story

Are you interested in having your story potentially featured in the Secure Start eNewsletter?

Email us at [securestartnewsletter@hollister.com](mailto:securestartnewsletter@hollister.com)

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