Secure Start Newsletter Q3 2015

We’re in This Together

Cover Story

20 Years of a Life Well-Lived
by Brenda Elsagher

CCFA Campus Connection

Secure Start services: Please Join Us!

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The mission of Hollister Incorporated is to make life more rewarding and dignified for people who use our products and services. That’s why we’re so excited to celebrate World Ostomy Day on October 3, 2015.

October 3rd isn’t just another day for us.

World Ostomy Day is a chance to celebrate with those whose lives have been touched and improved by ostomy care. We’re proud to be part of it!

Most people in our communities are not familiar with ostomies and how beneficial they are to patients and families. World Ostomy Day is a great way to change perceptions for the better.

“When managing a chronic illness or the huge changes in one’s life after ostomy surgery, attitude plays a big role. And knowing that we have allies out there – that makes a difference in keeping a positive attitude.”

— Susan Burns, President, United Ostomy Associations of America (UOAA)

We are sponsoring and participating in the WannaWearOne Ostomy AWEARness 5K races in Durham, North Carolina, Kingsport, Tennessee, and Happy Valley, Oregon on October 3rd. These events aim to provide a fun, community-driven experience that also serves as a platform for teaching people that ostomies do not limit people’s lives. Rather, they can improve them.

During the 5K, all participants wear an ostomy pouch as a sign of solidarity. If you can’t join us in person, visit www.ostomy5k.org for information on the virtual races happening nationwide. You can also easily donate to WannaWearOne online. See article on page 9 for more details about the event.

We are promoting awareness with Get Your Guts In Gear to distribute Inflammatory Bowel Disease (IBD) & Ostomy Awareness Ribbons at the 5K races and at local UOAA events. The ribbons were created by Lois Fink and Barb Wodzin, who have each had challenges with Crohn’s disease.

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From the beginning, this gutsy ribbon has done more than look stylish; it addresses the negative perceptions surrounding IBD and ostomy surgery. The design and color combination — a rich, dark brown with cream-colored lettering and a small red crystal, representing an ostomy — jump-starts dialogue that leads to awareness, acceptance, education, and empowerment.

“For the first time in 19 years, I experienced a life free of pain. No longer did I have to worry about finding a bathroom, or my body betraying me. You can live life to the fullest without a colon and rectum. And I’ll never have to go through a colonoscopy again!”

– Lois Fink, inspirational speaker and owner of the IBD & Ostomy Awareness Ribbon

We are inviting Wound Ostomy Care nurses who want to show their support for the ostomy community to participate in the WannaWearOne Campaign. We’re in this together!

Fun fact: The WannaWearOne 5K was created by two WOC nurses! Lara Leininger and Angela Richardson had a desire to raise the level of awareness around ostomy care, so they did something about it. They designed and launched the first annual 5K on October 4, 2014.

We’d love to hear any ideas you have on raising ostomy awareness! Please write us at securestartservices@hollister.com and include your pictures, stories, or thoughts.

We’re in this together! Celebrate World Ostomy Day with us on October 3rd.
Years ago, when I had relentless pains in my butt, I never thought it would lead to a life of happiness, challenge, education, serenity and humor. On October 2, 1995, I was diagnosed with colon cancer.

“There’s no easy way to tell you this without the biopsy results, but I’m almost one hundred percent sure you have cancer of the rectum; I’ve seen this before,” said the austere doctor.

How does one who never had a bowel issue, who didn’t even know about bowel diseases like ulcerative colitis and Crohn’s disease, end up with a golf ball-sized tumor in the poop chute? Cancer of the rectum? I had heard of colon cancer and colorectal cancer, but cancer of the rectum was not a diagnosis I had ever heard of. “Because of the location of the tumor, you will have your rectum removed, live with a colostomy and you’ll need vaginal reconstruction and a hysterectomy as well,” said the doctor. “Geez, don’t you need your rectum?” I naïvely said. “I am going to need another opinion.” I was the mother of two under six years old and terrified!

Thus began the first of ten appointments with ten different specialists with ten vaginal and rectal exams. I had areas photographed I didn’t know were possible and not the kind of photos you share at a party! It was embarrassing and after each one I would cry hard for five minutes and then like a water faucet, turn it off. Even so, there were moments where people made me laugh and I consciously started to seek out humor around me, which helped me cope.

Three weeks later, my doctor (who by now I referred to as the “Rear Admiral” behind his back), did the surgery which saved my life. Earlier he had told me that if the cancer had spread to my liver or lungs, they wouldn’t do the surgery, but make me as comfortable as possible.

“No, I want you to do this surgery; I will deal with the colostomy,” I said. “I want to dance at my childrens’ weddings.” “That attitude will help you get through this in the months ahead.” The Rear Admiral smiled for the first time.

Those months ahead were tough. I had many problems with wounds, diarrhea, pouch slippage, hernias, and hematomas. Plus I had three more surgeries over the next two years. There were tears and there was laughter and I depended on many people for support.

I refused to be stigmatized by having an ostomy. Instead I began to talk about it at work and at church and I followed through on a goal I made to become a comic by my 40th birthday. Then I took it further and tried out for the Twin Cities Funniest Person contest and beat 150 other young, hip comedians. Instead, this matronly, forty-year-old mother of two won and was awarded $1,000! I told my husband I’d split it with him so I gave him $50.

An article came out about me in the local paper, and a church group of ladies wanted me to speak at their event. I had to call the leader back. “I am not a professional speaker; I barely have 5-10 minutes of comedy material.” “Oh, just come and share your story about colon cancer and the importance of screening and throw in your jokes.” It will be fun she assured me. I discovered it was speaking I loved, even more than comedy, and I haven’t stopped talking since. It is my mission to inform people to get a simple colonoscopy screening—a test that can easily save their lives.
I went to college after this awakening with cancer, and discovered a love of writing. I wrote my first book as part of my college class and got an A! I discovered a niche market for my books, and learned more about bowels and butts from the hundreds of people I interviewed than I could have ever imagined. After the success of my first book, Hollister encouraged me to write more books and create "Humor and Healing from the Patient’s Perspective," a talk I give to healthcare professionals.

This life brought me into the world of professional speaking, and for the past few years I have taught the Speaker’s Academy Program for emerging speakers at our National Speaker’s Association group in Minnesota, along with having served as President of our association. I have also been involved with the Humor Academy program of the Association of Applied and Therapeutic Humor (AATH) for the last three years. We study the importance of humor in life situations and I will graduate in 2016 as a Certified Humor Professional. I wrote a book for the academy called, Your Glasses Are on Top of Your Head. Tales of Life, Longevity and Laughter. I am the 2016 conference chair for their event in Phoenix, Arizona April 7-10. Want some fun? Come along!

To celebrate twenty years of a great life, I will be hosting a comedy celebration in Bloomington, Minnesota with five comics, a reception for the contributing authors of my latest book, and a book signing. Proceeds from the show will benefit local and worldwide ostomy organizations. We will also acknowledge World Ostomy Day the next day. I hope to have some media there to help raise awareness.

What started off with such dreadful news turned into a life of opportunities, fun challenges, and the blessings of friendship. Great satisfaction comes from hearing laughter over something we never thought we would laugh about, from making a difference in someone’s life to simply seeing a nurse smile when she or he hears how grateful we are as patients.

This past June, I found The Rear Admiral’s address online and sent him a letter of gratitude. I let him know that my son was getting married that week and I would be dancing at his wedding. He had given me a second chance with that life-giving surgery. Life is good and I am happy to be alive.

Brenda Elsagher is an international speaker, author and comedian. Her books: 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. www.livingandlaughing.com. You can order Brenda's books through Amazon.com and she welcomes hearing from you. Brenda@livingandlaughing.com  
Office: 952.882.9882
Secure Start Corner

Meet the smile behind the voice

Jaclyn
Region: Southeast
Title: Lifetime Service Coordinator
Length of Service: 1 year 6 months
Hobbies: Going to the dog park with my puppy Ruby, reading, and traveling. I also love spending the day at the beach or on a boat, and then ending the day with a BBQ and bonfire with friends.
Favorite TV Shows: I’m currently binge-watching Gossip Girl, I can’t get enough of it. I have seen every episode of Friends, Law and Order SVU, and Sons of Anarchy at least 5 times each.
Interesting Tidbit: In January I got engaged on a trip to Jamaica and am having the most fun with wedding planning!

Brandon
Region: West Coast
Title: Acute Care Coordinator
Length of Service: 1 year 6 months
Hobbies: Painting, cheering on all of our Chicago sports teams
Favorite TV Show: Game of Thrones, Friday Night Lights and The Simpsons, which will never get old for me
Interesting Tidbit: I can play the guitar.

Jayme
Region: Northeast
Title: Supervisor, Lifetime Services
Length of Service: 3 years
Hobbies: I love watching sports (Go Bears, Hawks, Cubs and Michigan State). I enjoy taking road trips, playing cornhole, and DIY projects
Favorite TV Shows: The Blacklist and The Voice
Interesting Tidbit: I love karaoke and writing jingles.
CCFA Campus Connection Goes Viral

College students log on to support, friendship and fun

Adjusting to college life, especially away from home, can be difficult for anyone. For students living with Crohn’s or Ulcerative Colitis, the prospect of adjusting to this new way of living can be particularly daunting. So many questions arise. What happens if I have a flare up and I’m hundreds of miles away from my physician? Do I tell my dormmates about my condition? What foods can I eat on campus? The (CCFA) Crohn’s and Colitis Foundation of America has come up with a smart solution.

The Campus Connection website [www.ccfa.org/campus-connection](http://www.ccfa.org/campus-connection) is a multi-faceted resource, an all-nighter library of sorts for students living with IBD (Inflammatory Bowel Disease). Let’s take a tour of its knowledge:

**College Life**
This section provides a wealth of information on topics to be aware of for a smooth transition to campus life. For example, before the school year begins, it’s important to check in with the school’s disability support services, find a gastroenterologist near campus (if far away from home), and learn how to navigate your healthcare insurance plan. For questions related to dorm and apartment life, the site provides helpful articles about sharing your condition with new friends, tips for eating healthy and pointers for overcoming challenges that may arise such as finding convenient washrooms and avoiding drugs and alcohol.

**Connect with Others**
The heart of the Campus Connection site is its ability to let students know that they are not alone. Click on this tab to find a map of the United States featuring colorful “pins” which represent other students on college campuses. Click on a pin to find profile information about these students, their colleges, and IBD-related events and support groups. Students can add themselves to the map and begin connecting with others through the CCFA Campus Connection Facebook page. Here, students exchange advice and tips, share personal stories and provide moral support.

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Get Involved
Since students with IBD know firsthand about its effects, there are many ways to pay forward the support they’ve gotten along the way. Just by volunteering time and skills, anyone can make a big difference in the life of someone living with Crohn’s or Colitis. These include participating in CCFA events or taking the initiative to start something new. Students can:

• Join Steps to be Heard, CCFA’s nationwide fundraising walk program
• Participate in Team Challenge endurance training program
• Become a summer Camp Oasis counselor for children with IBD
• Join the National Council of College Leaders (NCCL) to help increase awareness of Crohn’s disease and ulcerative colitis through youth-focused advocacy fundraising
• Start a support group on campus

The Campus Connection site also calls out events, news and how to find a local CCFA chapter. Apart from being an advanced placement course in how to navigate college life, it’s a colorful, fun place to visit between writing papers and cramming for exams. In short, required reading for all students living with IBD.

Check it out at [www.ccfa.org/campus-connection](http://www.ccfa.org/campus-connection).

Campus Nutrition 101

Everybody is different but here are some foods that can help avoid and soothe diarrhea and cramping for those with inflammatory bowel disease:

• Bananas
• White bread
• White rice
• Cheese (if you’re not lactose intolerant)
• Gatorade or Crystal Light diluted with water
• Fruit juices
• Applesauce
• Smooth peanut butter
• Bland soft foods such as crackers made with white flour
• Plain cereals
• Refined pastas
• Broth
• Canned varieties of fruit
• Cooked vegetables
• Potatoes without skin
• Broiled or steamed fish
• Using canola and olive oils
• Small and frequent meals

For more diet and nutrition information, go to [www.ccfa.org/campus-connection/college-life/nutrition-diet/](http://www.ccfa.org/campus-connection/college-life/nutrition-diet/).
When the average person hears the word “ostomy”, he or she is often not quite sure what it entails. Most people understand that a person with an ostomy wears a pouch, but how does it work? Is it bulky and uncomfortable? Does it show under clothing? Now your loved ones, friends and even co-workers can find the answers to these questions thanks to a campaign launched by the United Ostomy Associations of America.

The WannaWearOne groundbreaking campaign invites people to wear an ostomy pouch for three days and go about their lives—working, playing sports and sleeping. It’s a fun, community-driven experience teaching people that ostomies do not limit peoples’ lives, but in fact can improve them—allowing them to get back to the activities they love.

Here’s how you can get involved:

• Recruit people to agree to wear an ostomy pouch for three days
• Pick a date when everyone will start, and each day the participants are given instructions to make it as realistic as possible
• Sponsor a party at the end of the three days

Give your participants these instructions:

Day One: Just attach the pouch and go about your day
Day Two: Put water, applesauce or some other substance into your pouch to give the feeling of a full pouch
Day Three: Remove your pouch and share your adventures and experience with other participants at a party

Encourage your participants to take photos of themselves involved in activities while wearing their pouch. These could include exercising, biking, swimming—even playing team sports. The more exciting the better! Why not hold a contest and give awards for the best photos? Then send your winning photos to [www.wannawearone.org](http://www.wannawearone.org) to be posted on the site in the “Show Us Yours” section. There’s even a section on the site for testimonials. It’s a great way to raise ostomy AWEARness!

What are you waiting for? Start making a list of possible participants and go to [www.wannawearone.org](http://www.wannawearone.org) for more information and inspiration.
Get Active and Get Involved

Head outside this fall and make a difference

Everybody knows that activity is an integral part of staying healthy. An ostomy shouldn’t keep you from doing the fall activities you love like hiking, biking and even running marathons! This fall, why not get moving to raise awareness about Crohn's disease, colitis and colon cancer? Check out these great awareness-raising activities available this fall:

**Take Steps for Crohn's & Colitis**
Take Steps is a nationwide event in 145 communities across the country to help the Crohn's & Colitis Foundation of America (CCFA) get one step closer to a cure. Through a series of Take Step walks family, friends and communities help raise critical dollars while enjoying live music, food and kids’ entertainment. As always, educational materials are available so that others can learn about Crohn's & Colitis and join the fight for a cure.

Find a Take Steps walk in your area by going to [www.ccfa.org](http://www.ccfa.org). Just plug in your ZIP code and get ready to make a difference.

**Girls With Guts Retreat—October 9-12, 2015**
The Girls With Guts Retreat is a weekend-long event providing opportunities for women ages 18 and over, with IBD and/or ostomies, to foster friendships and learn ways to improve their lives emotionally, mentally and physically. Though creating networks with other women is key, the weekend is packed with educational opportunities including speakers who bring a wealth of knowledge specific to women with IBD and/or ostomies.

The Girls With Guts 2015 Retreat is being held at YMCA Camp Collins in Gresham, Oregon. For more information, go to [www.girlswithguts.org](http://www.girlswithguts.org).

**Get Your Rear in Gear®**
Get Your Rear in Gear is the signature event of the Colon Cancer Coalition, and the largest, colon cancer-focused event series in the United States. These 5K races not only raise funds, but also help increase screening rates and awareness for colon cancer. Marathon-quality medals are given to the top finishers in several groups. Get your rear in gear and sign up for the next race, volunteer to drive someone you know to their colonoscopy or make a gift to the Colon Cancer Coalition.

Find a race in your area by going to [www.coloncancercoalition.org](http://www.coloncancercoalition.org).
Youth Rally 2015 Wrap Up

Inspiration climbs high in Boulder

Imagine being a young person between the ages of 11 and 17 with a bowel or bladder dysfunction and meeting a hundred or so other young people who can totally relate to your life experience. That’s the beauty of the Youth Rally, an amazing summer camp whose motto is “You are not alone.”

Campers flocked to the University of Boulder, Colorado from all corners of the country July 13-18 for fun, connection and inspiration. Not only did young people have an opportunity for dancing, rock climbing and swimming, but also enjoying themselves at Elitch Gardens Theme Park and a laser light show in the Planetarium at the University of Colorado.

The high point of the Youth Rally was inspirational speaker, Jen Bricker, an acrobat and aerialist born with no legs. Her story of never using the word “Can’t” touched the young people right to the core, and helped them understand that everyone has the same opportunities to achieve their goals regardless of medical or physical differences.

Of course there were educational sessions about medical conditions, products and management techniques as well as lots of shared stories and invaluable bonding. Bret Cromer, longtime Youth Rally counselor and this year’s Transportation Coordinator shared this story of a young camper:

“A 12-year-old boy in our group learned how to empty his pouch all by himself for the first time and opened up to the group, exhibiting self-confidence that his parents had never seen before.”

This is just one story of how the Youth Rally changes lives—there are hundreds of others.

The 2016 Youth Rally is planned for July 25-30 at the University of Washington in Seattle, Washington. Know a young person who would benefit from this life-changing experience? Go to www.youthrally.org.
Secure Start services

We Want You To Join Us

You talked. We listened. And we’re not stopping there.

What matters most to you, matters more to us. By listening to you, we can be sure the new services we offer today and in the future, are focused on your biggest concerns and needs as a person living with an ostomy.

So, what have we heard? You indicated a need for more information on managing skin-barrier leakage and skin irritation. This topic will be the focus of our first session in our NEW educational webinar series launching soon.

Secure Start services provides personalized support at no cost to you, so you can live your life, your way. Enroll today to learn more about the new services created with you in mind and how Secure Start services can help you today, tomorrow, and for a lifetime. www.securestartservices.com

Secure Start services has a new Facebook page!

This is a great place to meet people, whether you are living with an ostomy or caring for someone with an ostomy. Our Facebook page is the place we share our celebrations and events, photos, videos, and even recipes. And we invite you to share your stories too! Join the conversation today by clicking the link above. Welcome to the Family!
Share Your Story

Are you interested in having your story potentially featured in the Secure Start newsletter? Email us at securestartnewsletter@hollister.com

Secure Start Newsletter Resources

Secure Start services
1.888.808.7456
www.hollister.com

United Ostomy Associations of America, Inc. (UOAA)
1.800.826.0826
info@uoaa.org
www.ostomy.org

Wound, Ostomy and Continence Nurses Society (WOCN)
1.888.224.9626
www.wocn.org

Crohn’s & Colitis Foundation of America, Inc. (CCFA)
1.800.932.2423
www.ccfa.org

Inspire.com
www.inspire.com
It's Personal.
We are proud to offer a lifetime of personalized support for as long as you need us so you can live your life, your way.