

**Secure Start** *It's personal.*

# *eNewsletter*

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## FEATURE STORY

# Social Superhero

## Sara Ringer uses the power of social media to educate and support

Wonder Woman and Supergirl move over— Gut Girl is here to battle Inflammatory Bowel Disease (IBD). She wears a colon on her headband, an ostomy bag filled with glitter and a large G floating above some guts on her chest. And, of course, all good superheroes wear a cape!

By day, Gut Girl disguises herself as Sara Ringer, a gutsy blogger with Crohn's disease who came up with the Gut Girl character when she was a counselor at Camp Oasis, a summer camp for kids with Crohn's disease and ulcerative colitis. All fun aside, Sara has become a superhero in her own right, not only for people who can relate to her journey, but also for those learning about IBD. Her website "Inflamed and Untamed" is an uninhibited collage of photos, educational materials, shared stories, event info and swag. One look at the site and you'll see that Sara's superpower is complete honesty.

"I was not open about my situation for the majority of my life and had no one to connect with," explains Sara. "And then I realized that the best way to make an impact on people was to be really vulnerable and expose everything—like depression, relationship struggles and being intimate with someone for the first time."

*Wonder Woman and  
Supergirl move over—  
Gut Girl is here!*



Sara's journey with IBD started when she was ten months old. Gastrointestinal issues had her in and out of the hospital at least once a year until she was nine. An official diagnosis didn't come until she was 13—ulcerative colitis (UC). Fast-forward to college when her condition became so severe that her doctors removed her colon and rectum resulting in a temporary ileostomy, and then a J-pouch. Three years later she found out her original diagnosis of UC was incorrect and she actually had Crohn's disease. A third emergency procedure repaired a life-threatening obstruction.

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**Sara is not afraid to be vulnerable and expose struggles so that others can relate.**

## FEATURE STORY

## Social Superhero

*(continued)*

After her ileostomy surgery in 2008, the only information Sara could find was geared toward elderly patients. She felt alone with no one to answer her intimate questions like, “Will this ruin relationships for me?” and “Will guys find my body super-repulsive?” That’s why she feels that social media is such an important tool for the ostomy community.

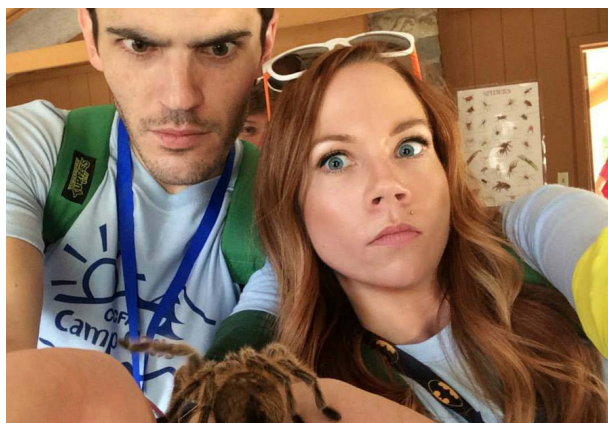
“It breaks down the isolation,” she says. “It takes your situation and normalizes it. You can turn to the Internet and find someone who can give you answers.”

Sara really had no idea she’d be doing patient advocacy. The impetus came from a YouTube video she recorded to tell her IBD story in 2011.

“Now that I look at it, it was actually embarrassing,” says Sara. “I said ‘um’ about 500 times! But then I was getting a lot of comments and people asking me questions. I realized I could really make a difference for others with IBD.”

*“It breaks down the isolation. It takes your situation and normalizes it.”*

Her website/blog was born soon afterward. Sara taught herself graphic design and video editing, and even purchased professional video equipment and lights. Facebook and Twitter came next. Her boyfriend, Dan, who remains her biggest supporter and advocate, helps iron out any technical issues.



**Sara’s blog “Inflamed and Untamed” is full of photos, educational materials, shared stories and event info.**

Sara’s reach is growing and people are noticing her talent for bringing people together. In 2015 she was invited to be one of eight experts to plan the first HealthVoices Conference. Over 100 online health advocates, who educate via social media, came together in New Jersey to share insights and ideas about how to strengthen online communities. The conference was such a success that it will become an annual event.

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## FEATURE STORY

## Social Superhero

(continued)

Though Sara is a big supporter of online sharing, she cautions newly diagnosed patients to take online information and advice with a grain of salt.

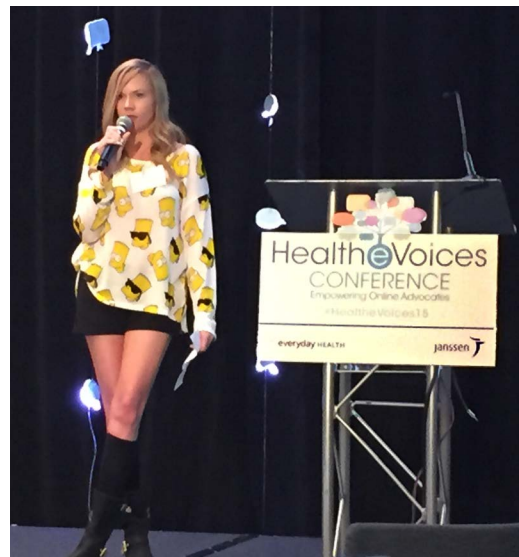
"The sites you visit need to list their sources," says Sara. "Keep asking yourself, 'Does this sound right?'. The best thing is to listen to your doctor." For reliable information beyond your doctor, Sara suggests IBD centers because many of them have patient education nights. The Crohn's and Colitis Foundation of America (CCFA) site provides excellent basic knowledge, and the University of Michigan IBD Center has a great online video series.

What adventures are up next for Gut Girl? A book for kids with Crohn's disease is in the works featuring the superhero in all her glory. Sara and four others are working on a peer-mentoring program for young adults at the University of Chicago's IBD Center. Sara is also partnering with a medical professional for a patient education night at the University of Michigan IBD Center. Most exciting, however, is a patient meet-up she and her boyfriend Dan hope to expand called "Gut Over Here You Guys!" Whatever the need may be in the future, Gut Girl and Sara are ready to fly in and be of assistance.

"My core mission has always been and always will be education and support," concludes Sara. "It's about getting people to relate to me and know they're not alone, to say 'Me too—I've gone through that.'"

Visit Sara's website/blog at [inflamed-and-untamed.com](http://inflamed-and-untamed.com).

*Financial Disclosure: Sara Ringer received compensation from Hollister for her contribution to this eNewsletter.*



Sara speaks at the HealthVoices Conference

## ASK THE EXPERT

# Don't be Afraid of the Water

## Here's some advice about bathing and showering with your ostomy

by Karen Spencer RN BN ET

Senior Manager Clinical Education, Hollister Incorporated



Karen Spencer

Your transition from the hospital to home can often be very overwhelming. People with a new ostomy have many questions, and one common concern is bathing with an ostomy. They may fear that the barrier and pouch will fall off with excessive water or heat, or question the length of time required to dry the pouch once wet. Check out these commonly asked questions, advice and helpful tips to make your regular shower or bath routine a pleasant experience.

### Q: Should I take my pouch off when I bathe?

**A:** You can shower or bathe with your skin barrier and pouch in place. Generally, the adhesion and security of your pouching system will not be affected by the water. However, if you enjoy long hot baths or hot tubs, you may experience shorter barrier wear time and may need to change your pouching system more frequently.

### Q: I have a two-piece system. Should I keep the pouch on the barrier when I shower?

**A:** Always shower with your pouch secured to the barrier. Removing a pouch from a two-piece system before showering will allow the water to come into contact with the barrier and loosen the adhesion. You may find it convenient to switch to a different pouch for the shower or bath so your regular pouch remains dry at all times.

### Q: Can you recommend an easy way to dry the pouch after bathing or showering?

**A:** Patting dry with a towel or using a hair dryer on a cool setting may help dry the pouch and tape around the barrier so it doesn't remain wet.

### Q: Should I add extra tape to the barrier when showering?

**A:** It is not recommended to add any additional tape to the barrier when showering. The additional tape may cause skin irritation when removed after each shower. If necessary, you can dry the tape on the barrier after showering with a towel or with a blow dryer on a cool setting.

### Q: Can I shower without my pouching system?

**A:** Yes, you can shower without your pouching system in place. Water will not harm or flow into your stoma, but you should avoid a forceful water stream directed right at your stoma. Remember that your stoma may be active during this time. If you have a fecal ostomy, over time you may be able to predict when the ostomy will not function and bathe or shower during that time. Please note that a urinary stoma will function frequently.

### Q: Will soap affect the adhesion of my pouching system?

**A:** If you use bar soap when showering, make sure it does not contain lotions or creams that may leave a residue on the skin which can interfere with the barrier adhesive. Rinse the skin well around your stoma with water and dry it completely before you apply your new barrier and pouch.

Showering or bathing is part of everyone's daily routine whether they have an ostomy or not. These helpful hints and suggestions will help you become more comfortable and confident living life with an ostomy.

If you have any further questions about showering and bathing with an ostomy, please call your dedicated Secure Start services coordinator at 1.888.808.7456.

NEWS FROM HOLLISTER

# Secure Start Corner

Meet the smile behind the voice



## Mary

**Region:** Southeast  
**Title:** Lifetime Service Coordinator  
**Length of Service:** 14 Years

**What is the best trip you have ever taken?**

When my children were younger, we would take family trips up to the northern woods of Wisconsin.

**If you could be someone else for just one day, who would it be?**

I would like to be Frank Sinatra and hang out with the Rat Pack.

**What are the top three things on your bucket list?**

1. Go to Ireland
2. Take a road trip down the Pacific Coast from Seattle to Long Beach
3. See Victoria Falls



## Jeff

**Region:** Northeast  
**Title:** Lifetime Service Coordinator  
**Length of Service:** 8 years

**What is the best trip you have ever taken?**

I went to an all-inclusive resort in Cancun, Mexico.

**If you could be someone else for just one day, who would it be?**

I would like to be Michael Jordan the day we won the NBA championship.

**What are the top three things on your bucket list?**

1. Go to Mount Rushmore
2. Visit Washington, DC
3. See the Grand Canyon

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## NEWS FROM HOLLISTER

## Secure Start Corner

*(continued)*

## Nate

**Region:** Central  
**Title:** Lifetime Service Coordinator  
**Length of Service:** 9 Years

**What is the best trip you have ever taken?**

Taking my daughter to Disney World for her fifth birthday. She got to see all the characters she saw on TV while growing up.

**If you could be someone else for just one day, who would it be?**

As a kid, I dreamed of being Michael Jordan and playing in the NBA.

**What are the top three things on your bucket list?**

1. Go whitewater rafting
2. Travel to National Parks like Mount Rushmore, Yellowstone, and the Grand Canyon
3. Travel to amusement parks across the country



## Alice

**Region:** Southeast  
**Title:** Lifetime Service Coordinator  
**Length of Service:** 6 years

**What is the best trip you have ever taken?**

I have many "best" trips, all different, all special.

I will share one with you ... Several years ago, my husband and I went to Europe for almost a month. We were able to visit some of his family in Poland. We experienced an overwhelming feeling of sadness while visiting Auschwitz, but later that day, we traveled to the beautiful town and home of the late Pope John Paul. We took the Euro Rail down to Vienna and then to magnificent Rome, which is full of history, beautiful art and wonderful food.

**If you could be someone else for just one day, who would it be?**

A scientist studying whales or wolves, or a scientist studying global warming.

**What are the top three things on your bucket list?**

1. Travel to Iguazu Falls, Argentina and visit Argentina's wine state of Mendoza
2. Go to South Africa
3. Visit Halong Bay, Vietnam

## EVENT UPDATES

# Get Your Move On

Choose an event this year and join the cause

## Take Steps for Crohn's & Colitis™

The Crohn's & Colitis Foundation of America (CCFA) Take Steps walks offer a wonderful way for family, friends and the IBD community to celebrate the hard work and dedication of their participants to raise funds toward their mission. These walk events are filled with live music, food, kids' entertainment and educational materials. By joining the Take Steps community, you will fundraise to support mission-critical research and patient support programs for the 1.6 million Americans living with IBD. Join them in 2016! Take Steps is a nationwide event in more than 120 communities across the country. Walk as an individual or gather your friends, family and co-workers to form a team. Register at [cctakesteps.org](http://cctakesteps.org)



## Get Your Rear in Gear®

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. In 2015, the Colon Cancer Coalition celebrated the 11th 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.



## Run for Resilience Ostomy 5K

The WannaWearOne Ostomy AWEARness 5K is now the Run for Resilience! The third annual Ostomy 5K race will take place on World Ostomy Day on October 1, 2016 in Durham, North Carolina, as well as other locations still to be confirmed. The races will educate, support and raise community awareness about people living with an ostomy. In fact, participants are given an ostomy pouch in their swag bags and encouraged to wear it during the race! 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 on October 1. All proceeds benefit the United Ostomy Associations of America, Inc (UOAA). Go to [ostomy5K.org](http://ostomy5K.org) for more information and to sign up!



## Get Your Guts in Gear: The Ride for Crohn's & Colitis

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.

In 2015, the 12th Hudson Valley, New York Ride and the 2nd Sandusky, Ohio Ride were successes. Both Rides brought together new participants, veteran riders and crew members providing a very special bond and experience for all involved. The result was camaraderie and a wonderful sense of community. Register to ride or volunteer this year! For 2016 Ride information and registration, visit [igotguts.org](http://igotguts.org).





## EVENT UPDATES

# Mountains of Fun in Boulder

## Youth Rally 2015 changed the lives of people of all ages

One hundred and forty young campers experienced bonding, education and fun surrounded by the beautiful mountains of Boulder, Colorado at Youth Rally 2015. This amazing summer camp provides a non-threatening environment for young people ages 11 to 17 with any sort of bowel or bladder dysfunction.



*“I couldn’t think of anything else I’d rather do than to return and train to be a counselor.”*

Last year, along with education about medical conditions, management techniques and independent living, campers got a huge dose of inspiration and all-out fun. Motivational speaker Jen Bricker, world-renowned aerialist and acrobat with a disability, spoke about the power of never saying, “I can’t.” And Sean Ahrens, founder of Crohnology, spoke of the importance of self-advocacy and taking responsibility for our health management.

The excitement started with a casino night and continued with ice skating, a Laser Light show, an ice cream social, trip to Elitch Gardens amusement and water park, and the annual talent and fashion show. In between all of this activity, campers got together for self-esteem sessions and group discussions. The week ended with a Candy Land themed-dance.

Though this life-changing camp is for young people, the counselors and nurses who attend this amazing event also come away transformed.

“I am inspired by each kid’s story and their determination to not let any challenges they’re facing stop them from moving on with life,” says Bret Cromer, counselor. “I always learn something new from the campers, other counselors and about myself.”

Many counselors were once campers themselves and share their experiences of living with medical challenges with the young people. All look forward to returning year after year to connect and make a difference in the life of someone else.

Cody Mitchen, past camper, joined the counselor team in 2015. “Now that I’ve “graduated” (from Rally) I couldn’t think of anything else I’d rather do than to return and train to be a counselor. This is the least I can do for a community of people that has helped me so much. This past year I’ve had the opportunity to represent Youth Rally at some conferences and talk about the impact it has had on me. Not many kids my age get to speak to doctors and nurses about something like this; not only have I learned to better take care of my Crohn’s, but I’ve also learned how to be a better person.”

You, too, can make a difference! Your donation will help fund Youth Rally camper scholarships that are funded by community partners as well as individuals. Simply go to [youthrally.org](http://youthrally.org) for more information.

The 2016 Youth Rally will take place July 25-30 at the University of Washington in Seattle. Put it on your calendars now!



EVENT UPDATES

# Sisterhood Support

## The Girls With Guts™ Retreat Turns Strangers into Sisters

For 73 women with Inflammatory Bowel Disease (IBD), October 9–11, 2015, was a weekend they'll never forget. This multi-generational group from all over the country convened in Gresham, Oregon, at the third annual Girls With Guts retreat for support, education and empowerment.

The magic happens in a relaxing camp setting where participants are encouraged to share their stories. 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.

This year's retreat welcomed two fascinating speakers, a clinical psychologist and a registered dietitian, who work specifically with GI patients. Participant-led small groups allowed women to choose topics that fit their interests. These ranged from parenting and IBD to fashion for people with ostomies. Most exhilarating, however, was a foray into high-adventure with platform ziplining.

"I would humbly say that the Girls With Guts retreat changes the lives of people who attend," says Jackie Zimmerman, Executive Director and Founder. "Many don't

know anybody else with IBD when they come, and by the time they leave, they have a support network of 70 women that they can turn to with questions, concerns and support."

The next Girls With Guts Retreat will take place in East Stroudsburg, Pennsylvania, September 30-October 3, 2016. Registration opens in April. For more information and to sign up go to [girlswithguts.org](http://girlswithguts.org).

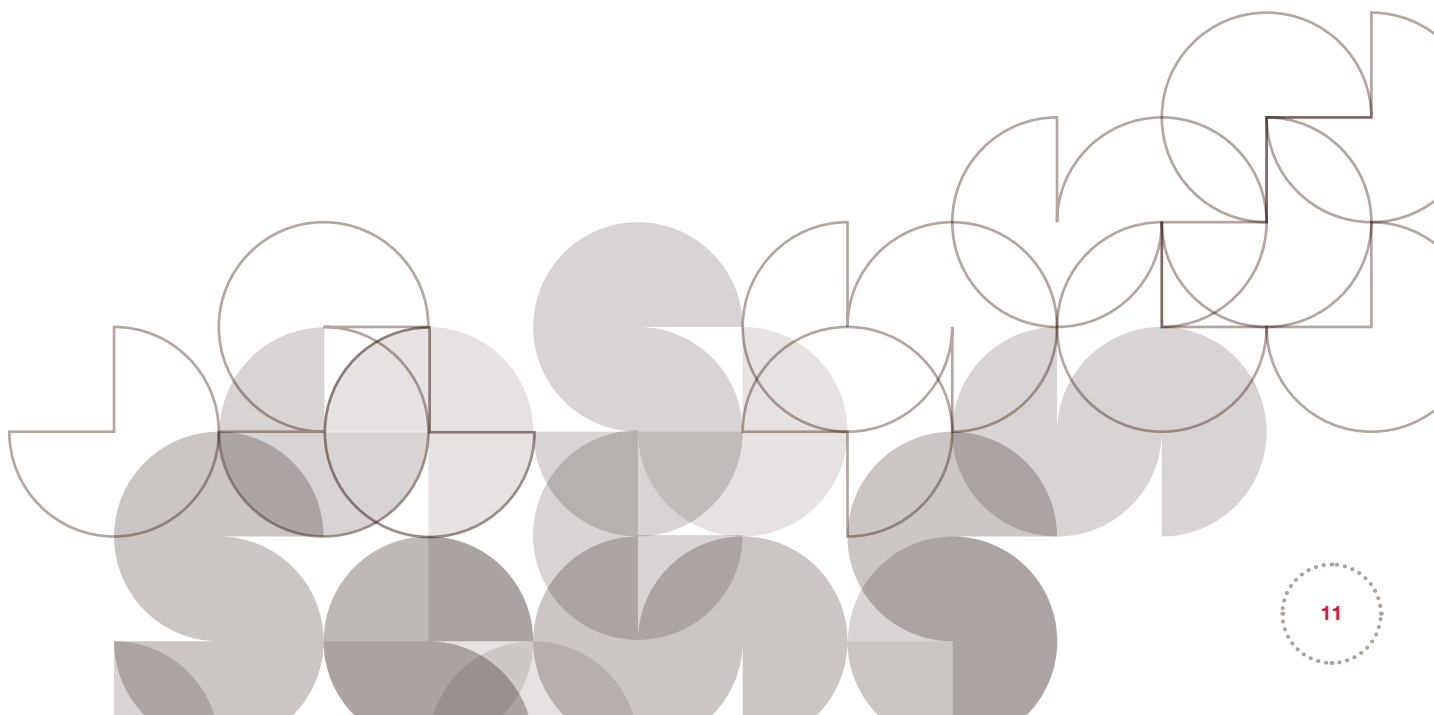


NEWS FROM HOLLISTER

# Our Website Just Got an Upgrade!



Check out our new website! Learn more about how Secure Start services offers a lifetime of support—you can even enroll online. You can also access the Hollister Incorporated Ostomy Care resource page with information to help you before and after ostomy surgery. Come visit us at [securestartservices.com](http://securestartservices.com)!



## WHAT'S SO FUNNY?

# What's So Funny?

## Brenda's back with her signature brand of gutsy humor

### Traveling with "The Kids"

From Brenda's latest book: *Your Glasses Are On Top Of Your Head*

Before my husband, Bahgat, and I were married, we traveled to San Francisco with our friends, Pat and Tom. Bahgat decided to be the designated driver for the entire trip and we loved that. We got into a routine of the two of us taking over the front seat and Pat and Tom being in the back. Bahgat started calling them kids on the trip and we were all pushing 30 years old at the time. "Where shall I drive you kids next?" was a common question before we headed off toward our next destination.

We arrived at the Exploratorium in San Francisco and my husband did his usual joking. As we arrived to the entrance to pay admission, my husband said, "Two adults and two kids please." Without hesitation, the cashier said, "Well, I don't believe those are your children, but I do believe you two are senior citizens," and gave us the discount and we happily went on our way.



**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)

## 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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PROMOCODE: SSNEWS0216

922973-0216



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