

Hollister Secure Start Services

eNewsletter

Q1 2019

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Let's talk about
peristomal
skin health

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FEATURE STORY



Gianna's dynamic personality shines through in everything she does

A Life Full of Glitter and Sparkles

Gianna Henrickson shines with positive energy

Gianna Henrickson nicknamed herself “Queen Bee,” and anyone who meets this plucky 5 year old understands why. She reigns over life with pure joy and an insatiable spirit of adventure. She can be found dressed as a princess at Disney World, dancing in a New York City Ballet workshop or screaming the loudest on the flag football cheerleading team.

“For a child that has been through so much, she has never let it take her down,” explains Gianna’s mother, Erica. “She doesn’t question any of it and it just gives her more sass and pizzazz.”

Born with central core myopathy, a condition that causes problems with the tone and contraction of skeletal muscles, Gianna uses a wheelchair and a pink, sparkly gait trainer. But to experience her positive attitude, you would never

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FEATURE STORY

A Life Full of Glitter and Sparkles

(continued)

know that her health issues go even deeper. Gastroparesis and dysmotility, which affect the muscles of the digestive system, necessitated an ileostomy in 2018. And a few months later, Gianna chose to have a urostomy due to a neurogenic bladder.

“Our urologist, Dr. Adam Howe, is phenomenal and gave us all of the options,” says Erica. “He believes that since it’s her body, she should have a say in what happens.”

“For a child that has been through so much, she has never let it take her down.”

—Erica Henrickson, mom of Gianna

While Erica was learning how to care for her daughter at home, she got assistance from Stephen Jones, an ostomy nurse at Albany Medical Center. “He became my guardian angel,” Erica proudly admits. “Nurse Stephen has the patience of a saint and the knowledge of an encyclopedia. I could call him in tears and he’d have the answers to calm me down.”

“He is an advocate of owning one’s ostomy and asked Gianna to name her stoma, explaining that it’s a part of who she is.” No one was surprised when she named her stoma “Sprinkles” and her urostomy “Candy.”

Within the first couple of weeks after ileostomy surgery, Gianna had bright red peristomal skin breakdown and terrible itching. Erica turned to the Hollister Secure Start services team for answers. Lynn Sacramento, RN, BSN, WOC Nurse, and Clinical Education Specialist at Hollister Incorporated, was there to help. After asking a series of questions, Lynn recommended a convex skin barrier with the right fit and formulation for her, which helped Gianna’s quality of life improve.

“One of the biggest things I like about Hollister Secure Start services is being able to pick up the phone and talk to a real person who cares,” says Erica. “It’s great to have a conversation with someone who wants to help fix the problem, not sell products.”

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Gianna’s mom says her medical obstacles just give her more sass and pizzazz

FEATURE STORY

A Life Full of Glitter and Sparkles

(continued)

When it comes to day-to-day life at the Henrickson home, Erica, along with her husband and mother, works hard to maintain a status quo.

“Sure, each of us has gone through our own stages of grief, but we have to make sure it doesn’t consume Gianna’s life,” says Erica. “I want her to have a life that’s full of glitter and sparkles, not tubes and stomas.”

Gianna’s three rambunctious brothers make sure she feels like any other sister. They treat her like one of them, and even taught her to ice skate in her gait trainer! Each one has a unique purpose in her life. Joey, age 10, is her protector; Vinny, age 9, is her hero; and her twin, Rocco, is her playmate. In fact, Vinny aspires to be a physical therapist when he grows up to give kids with disabilities the same care that Gianna has received.



Gianna has a special bond with her three loving brothers, Joey, Vinny, and her twin, Rocco.

“Vinny doesn’t see her as having medical issues,” says Erica. “He sees her as perfect, and even goes to appointments with us to learn about her various products and devices.”

Queen Bee has no shortage of friends, both with and without disabilities. She’s an active member of The Girl Scouts of America and on the cheerleading squad for the Mohawk Valley Challengers, a special-needs flag football team.

Erica remembers a time right after surgery when Gianna lifted up her shirt and showed “Sprinkles” to her friends. She explained how her ostomy and pouching system worked and ended the demonstration with, “Do you have any questions?” She also uses “Holly Hollister,” her Shadow Buddy doll, to explain her stoma, letting friends peel the pouching system off and put it back on.

“Not one of the little girls has an issue with any of it,” says Erica. “The more we normalize things like this, the more people know that none of us are Barbie dolls coming out of the factory.”

Erica’s advice to other parents of children embarking on ostomy surgery is to reach out on social media to other families who have experienced what you’re going through. Also it’s a good idea to peek at your child’s stoma for the first time before they come out of anesthesia so they don’t see any shock on your face. Remember that your child is looking to you to say it’s all going to be okay.

“Most of all be proud of your child and the strength that he or she has,” concludes Erica. “I am proud and honored to be Gianna’s mother, and I am proud of the person she has helped me to become. Anyone who has met Gianna has become a better person because of her.”



Erica Henrickson is a Special Education Teacher and Program Director for her family-run agency that services children with special needs. She is the mother of four children who keep her busy with sports, clubs, and extracurricular activities.

Financial Disclosure: Erica Henrickson received compensation from Hollister Incorporated for her contribution to this eNewsletter.

NEWS FROM HOLLISTER INCORPORATED

Hollister Secure Start Services Corner

Meet the smile behind the voice

Our team is passionate about helping Hollister Secure Start services members over the phone or by email. If you have a question about your ostomy, they're here to help. Get to know these members of our team!

Courtney



Title: Consumer Service Advisor
Serving you since: August 2018

What is the customer interaction you've had that you are most proud of?

A member felt defeated due to some problems she was having with leakage. After discussing different options with her, I sent some samples of products that would work best for her. A week later she called to say I gave her back her life and she finally felt comfortable to go back in public.

What are the three top values that drive you? Leadership, Teamwork, Growth

Favorite quote: "Success is not final, failure is not fatal: it is the courage to continue that counts." – *Winston Churchill*

Sianna



Title: Acute Care Coordinator
Serving you since: May 2016

What is the customer interaction you've had that you are most proud of?

I had the opportunity to present at a UOAA event. After the presentation, a consumer told me his story of how he battled with skin issues and struggled to find the right product. Hollister Secure Start services was able to introduce him to products that were right for him, and it was a game changer.

What are the three top values that drive you? Integrity, Dedication, Compassion

Favorite quote: "You miss 100 percent of the shots you don't take." – *Wayne Gretzky*

Julie



Title: Consumer Service Advisor
Serving you since: October 2012

What is the customer interaction you've had that you are most proud of?

I had a consumer with a urostomy who had consistent leaking. It turns out he simply was in the wrong type of pouching system. I mailed samples and followed up to see how they worked. He told me they worked great and the week after he got the products he took his whole family out to dinner and it was one of the best evenings he had in a very long time!

What are the three top values that drive you? Kindness, Integrity, Loyalty

Favorite quote: "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."
 – *Maya Angelou*

ASK THE EXPERT

Scratching the Surface of Peristomal Skin Itching

Clinicians explore the issue in two enlightening studies

If your skin is red or weepy under your skin barrier, or you have annoying itching but no visible signs of skin irritation, you are not alone.

Two clinicians, Ginger Salvadalena, PhD, RN, CWOCN, and Melissa Menier, MS of Hollister Incorporated, conducted two studies to explore how nurses and patients compared in their experiences with the issue of peristomal skin itching (also called *pruritus*), including in the absence of visible skin problems.^{1,2}

Participants included 164 people with stomas and 259 ostomy care nurses. Questions to the people with stomas ranged from “*What made the itching better or worse,*” to “*Did you ever talk to your healthcare provider about this itching sensation?*” Clinicians were asked about the number of patients who reported itching, as well as the common causes of peristomal itching based on their experience.

The research drew these conclusions:

- Peristomal itching was self-reported by **87% of people with stomas; 36% of the time their skin appeared healthy.**³
- **71% of the nurses recalled a time when their patients reported peristomal skin itching** and the skin was intact and free of redness.⁴
- Nurses encourage patients to report peristomal skin itching, however the people with stomas in this survey did not commonly report their itching to their healthcare providers.⁵



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ASK THE EXPERT

Scratching the Surface of Peristomal Skin Itching

(continued)

This research has also been the jumping off point for further exploration and conversations around skin health and itching, the often unspoken skin concern.

“I never realized even itching was a problem with my ostomy patients. I never asked them until [this] work about itching,” says Joyce Pittman, PhD, ANP-BC, FNP-BC, CWOCN, FAAN, Indiana University Health, Indianapolis, Indiana.

“Itching is interesting. I think that in my practice I haven’t paid enough attention to it,” adds Janice C. Colwell, RN, MS, CWOCN, FAAN, University of Chicago, Illinois. “I can envision some patients when we take a pouching system off and we’re cleaning their skin and they go, ‘oh that feels so good.’ And I say ‘what do you mean?’ and they say ‘it’s so itchy it just feels good when you’re just rubbing it.’ And I would say, ‘Oh,’ and I would move on because I didn’t know what else I would be able to do for patients.”

Now that clinicians are more aware of the problem, they continue to explore ways to help manage itchy peristomal skin, including when the skin looks healthy. If you experience peristomal itching, don’t hesitate to report it to your healthcare professional.

“I never realized even itching was a problem with my ostomy patients.”

—Joyce Pittman
PhD, ANP-BC, FNP-BC, CWOCN, FAAN

To learn more about this research, watch the video “Peristomal Itching Survey” under “Misconception #2” at hollister.com/ditchtheitch

Peristomal Itching Survey (2016)

PURPOSE: To explore peristomal itching when the skin was intact and free of redness

164

people living with a stoma





259

stoma care nurses










To hear more from these clinicians, watch the video “The ADVOCATE Clinical Trial: Authors’ Perspective” on the Hollister YouTube channel at youtube.com/HollisterIncorporated.

1, 3, 5 Consumer Survey of Pruritus, Hollister Incorporated, 2016. Data on File.
2, 4 Clinician Survey of Pruritus, Hollister Incorporated, 2016. Data on File.

NEWS FROM HOLLISTER INCORPORATED

Sometimes You See It, Sometimes You Don't

Check your knowledge of peristomal itching

The skin around your stoma should be intact without irritation, rashes or redness. But skin complications aren't always visible. Peristomal skin itching is a common occurrence. People living with a stoma and otherwise healthy peristomal skin often complain that "need to scratch" sensation.

"We recognize that skin health is so important to the people we serve," explained Elina Yufa, Associate Digital Manager at Hollister Incorporated. "Evidence has shown us the negative impact of peristomal skin complications on quality of life."

As a resource to you, we have devoted a website page with an interactive quiz on Hollister.com that uncovers the facts, addresses common misconceptions, and offers ways to help with peristomal itching.

Elina added, "People living with a stoma don't have to live with the cycle of unhealthy skin, and we want to be a part of making life more rewarding and dignified for them."



Start touring the page now hollister.com/ditchtheitch



Check out the **Peristomal Skin Assessment Guide for Consumers**



How much do you know about peristomal itching?

Click here to take the interactive quiz.



"People living with a stoma don't have to live with the cycle of unhealthy skin..."

—Elina Yufa

COMMUNITY SPOTLIGHT

See You in Seattle!

Applications are now open for Youth Rally 2019

From July 8 to 13, 2019, excited campers, counselors, and nurses from all over the U.S. will converge at the University of Washington in Seattle for the 2019 Youth Rally. This annual, life-changing summer camp provides a safe and supportive environment for people ages 11 to 17 living with conditions affecting their bowel and/or bladder systems. Though packed with fun, Youth Rally's ultimate goal is to encourage self-confidence and independent living. Hollister Incorporated is proud to be a Platinum Sponsor.



Youth Rally 2019 Application Deadlines:

- April 15 Counselor Position
- June 1 Nursing Position
- June 1 Camper Position



Many Youth Rally counselors were once campers themselves. Through their own life experiences with medical and surgical challenges, counselors have first-hand knowledge of what the campers are or may be facing and can provide the needed support to promote self-confidence and independence.

“The heart and strength of the campers is what motivates me 365 days a year to be my best self,” explains Emily Mallar, Youth Rally Vice President and counselor of 17 years. “What’s perhaps more awesome for me is having seen so many of these youth return year after year as they grow into incredibly amazing adults, accomplishing some incredibly amazing feats.”

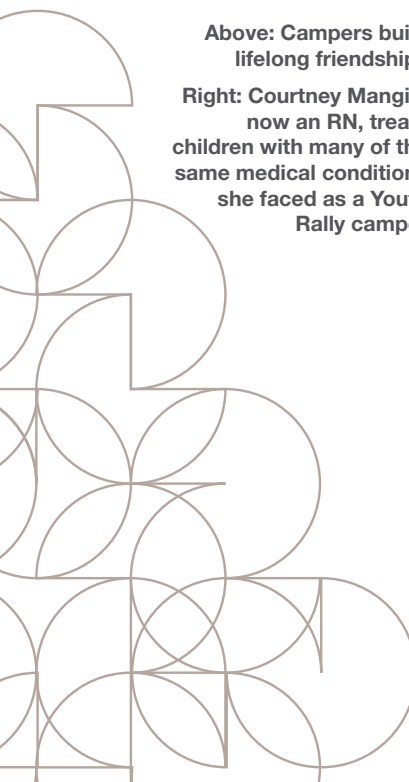
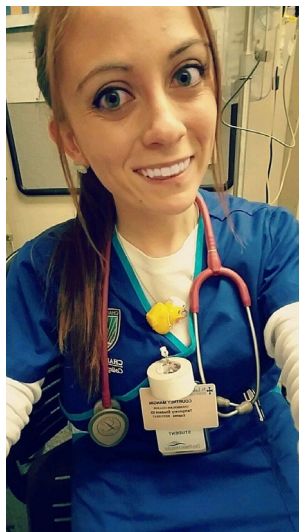
Courtney Mangin is one of the campers turned counselor that Emily has watched blossom into an inspiring young woman. Born with Spina Bifida, doctors didn’t expect her to live past her first birthday. At 25 she is a Registered Nurse working in the same operating room where she was once a patient. Now she heartily advocates for parents to send their children to Youth Rally.

“For the parents who are on the fence about sending their kiddos—my mom was so nervous to send me. It’s hard to let go of your child, but she’s so glad she did. It not only helped me, but helped her to know that I got to meet other kids like me and become more independent and confident,” says Courtney.

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Above: Campers build lifelong friendships

Right: Courtney Mangin, now an RN, treats children with many of the same medical conditions she faced as a Youth Rally camper



COMMUNITY SPOTLIGHT

See You in Seattle

(continued)

There are hundreds of young people like Courtney who have been encouraged by this nurturing camp. Counselor Cody Mitchem gives back to Youth Rally by speaking of its impact at conferences.

“This is the least I can do for a community of people that has helped me so much,” says Cody. “Not many people my age get to speak to doctors and nurses about something like this. Not only have I learned to take better care of my Crohn’s but I’ve also learned how to be a better person.”

Youth Rally also assembles a team of their own licensed medical professionals who have experience with wound, ostomy and continence (WOC) nursing as well as those with experience in pediatrics, trauma, medical, or surgical nursing. They volunteer their time to support the campers as needed, both physically and psychosocially as an extension of the counselor team.



Cody (second from right) has made many meaningful relationships while both a camper and a counselor for Youth Rally.

“Not only have I learned to take better care of my Crohn’s but I’ve also learned how to be a better person.”

—Cody Mitchem, Youth Rally previous camper turned counselor

Managing medical conditions is only a fraction of what Youth Rally 2019 will offer. Those five days in Seattle will also be rounded out with fun. Campers will create lifetime bonds with each other through games, swimming, field trips—even a fashion show and a “prom-like” dance. Motivational speakers will also be on hand to let the campers know they are not alone.

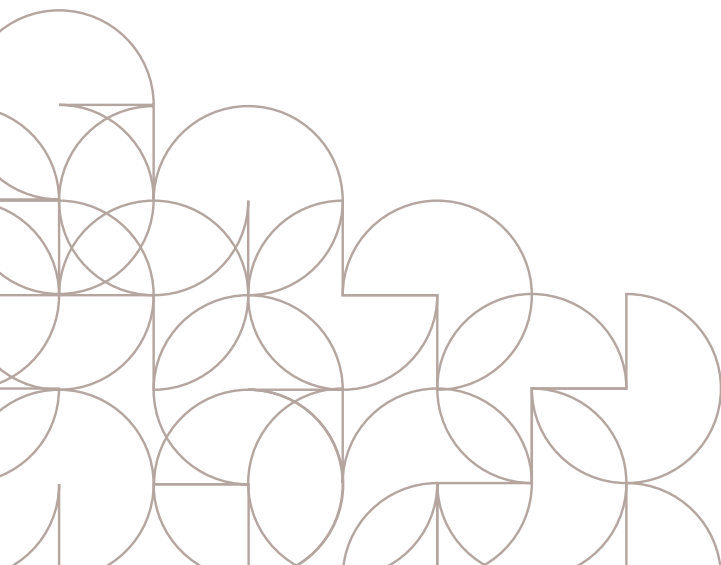
Applications are now open for prospective campers, counselors, and medical professionals. If you know of someone who would benefit from participating in or volunteering at the Youth Rally, please encourage them to apply. Sponsorship is available for campers, but all participants are encouraged to fundraise for themselves or others.

What are you waiting for?
Visit youthrally.org to learn more.

 **Apply to be a camper!**

 **Apply to be a counselor or medical volunteer!**

Hollister Incorporated is a proud Platinum Sponsor of Youth Rally.



EVENT UPDATES

2019 Coming Attractions

Don't miss these ostomy community events

Ostomy-Related Events

2019 is heating up with ostomy-related regional events from health and supplier fairs to education days and conferences. See below for a Regional Event near you!

11th Annual Iowa Ostomy Education Day

April 6, 2019: Waterloo, Iowa

Quality Life Association (QLA) 34th Annual Conference

August 22-24, 2019: Knoxville, Tennessee

For more information on these or other upcoming regional events go to ostomy.org/Conferences_and_Events.



The Crohn's & Colitis Foundation of America (CCFA)

Take Steps for Crohn's & Colitis™ and Camp Oasis

ALL AGES • NATIONWIDE

Take Steps walks offer a wonderful way for family, friends and the inflammatory bowel disease (IBD) community to come together to raise funds toward their mission. It's a nationwide event in more than 120 communities across the country. Register at cctakesteps.org.

Camp Oasis is a co-ed, residential summer camp program that provides kids with Crohn's disease or ulcerative colitis a safe and supportive camp community. Camps are held in 12 states. Find one near you at crohnscolitisfoundation.org.



Youth Rally

Youth Rally 2019

More than 30 years after its inception, the Youth Rally remains a community for young people to meet others who live with similar medical conditions. Lasting friendships are

formed in an atmosphere that promotes self-confidence and independence. Learn more about Youth Rally 2019 at youthrally.org.

AGES 11-17 • SEATTLE, WA



ALL AGES • NATIONWIDE

Colon Cancer Coalition

Get Your Rear in Gear

Walk, run or ride in the largest colon cancer-focused event series in the country. Get Your Rear in Gear Run/Walk and Tour de Tush Bike Ride are sponsored by The

Colon Cancer Coalition, a nationally recognized partner in the fight against colon cancer. This year, 45 events are planned across the nation. Find the one near you at coloncancercoalition.org or create your own local event!



ALL AGES • NATIONWIDE

United Ostomy Associations of America (UOAA)

2019 National Conference and Run for Resilience Ostomy 5K

Don't miss the seventh national **UOAA Conference** in historical Philadelphia. Attend inspiring talks, educational workshops and exhibits. New this year: tracks for Pediatric, Young Adults and Caregivers. Enjoy a Roaring Twenties party socializing with new friends from around the country, or explore all the area has to offer. Be sure to stop by the Hollister booth and also visit our educational sessions! Go to ostomy.org for more information and to register.

UOAA's annual **Run for Resilience Ostomy 5K** events are held to educate, support, and raise community awareness about people living with an ostomy. These races will feature a DJ, kids' activities, incentivized fundraising, an ostomate division, and awards. Go to ostomy5K.org for more information and to sign up!

Hollister Incorporated is a proud Platinum Sponsor of Youth Rally and Diamond Sponsor of UOAA.

WHAT'S SO FUNNY?

I Can't Stop Itching!

Brenda scratches right where it itches with humor

I've had my share of itching. I have a wooded backyard, and if I see a wood tick, I have a psychological urge to keep scratching. In my early Camp Fire Girl days, I once climbed into a patch of poison ivy and the pink splotches on my legs soon turned into an itchy mess.

It seems the more you feel that mosquito bite, the more you are compelled to scratch it. Unfortunately it never helps. I did some very thorough "research" through friends and family to ask for their remedies for a never-ending itch. Here is what my limited market research pulled up: Rub coconut oil or the tops of strawberries on the itch. Basil, peppermint or aloe vera leaves work for some folks too. Apple cider vinegar got a couple of nods, along with drinking several beers. Eat bananas and watermelons and then rub their skins on your itches. In a pinch, oatmeal paste or clay will do too. And there you have it.

Of course, none of these proposed home remedies would work well for itchy skin underneath an ostomy barrier. Putting any of these on the peristomal skin could interfere with the barrier's ability to stick to the skin – and the outcome of that could be worse than the itch!

Early on with an ostomy, I used to have terrible itches under my pouch and I hated changing it so I just left it. This was not a great plan. My skin suffered a lot from my irregular stoma, cutting my pouches too big, and products that didn't agree with me. It was trial and error for a very long time. After I had a couple more surgeries, the combination of antibiotics gave me a yeast infection around the stoma to contend with. At that time, I used a lot of paste, but there



are so many better products these days. It's been a long time since I had an itch around my stoma. The best thing to do if you have an itch is to probably check out your flange to see if it's been compromised. Once stool or urine gets on the skin it can wreak havoc.

I've also found that having your hands down your pants in public is just not a good look. People will wonder about you.

I'll leave you with one last tip I read about on the internet – press a charge card along the itch and it will go away. I have my own theory about that. I went shopping while suffering from an itchy sunburn, took the charge card out, bought a new purse, some makeup and a cute dress and forgot about the itch all together. That card tip really worked!

**Please note: The content of this article is not meant as medical advice. If you have peristomal skin itching, please consult your ostomy care nurse or healthcare professional.*



Brenda Elsagher is a loud and proud member of the ostomy community and a good friend of Hollister Incorporated. She is an international keynote 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*. you can find out more about her at livingandlaughing.com.

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

NEWS FROM HOLLISTER INCORPORATED

How Are We Doing?

We're looking for your opinions! Let us know your thoughts about the Hollister Secure Start services eNewsletter. We strive to make it a reflection of your needs and wants, so please take a few moments to fill out the following questionnaire.

Thank you in advance!
Your friends at Hollister Secure Start services



Stay Connected

Let us know what's going on with you

Once you're a member of Hollister Secure Start services, you're always a member. That means you can turn to us weeks, months or years from now with questions that may come up about managing your ostomy.

Did you find what you were looking for in this issue about peristomal skin itching? If you have questions about accessories or other areas of your life as an ostomy user, we can help! We are always on the hunt for new solutions to help you throughout your ostomy journey.

Click on the button at right and share your contact information so we can be sure our records are up to date. It only takes a few moments—for a lifetime of personalized care. We look forward to hearing from you soon!



We're here to help! If you haven't already enrolled, call us today at **1.888.808.7456** or visit our website at **securestartservices.com/ostomyenroll** to get started.



“I want her to have a life that’s full of glitter and sparkles, not tubes and stomas.”

—Erica Henrickson

Share Your Story

The right words can brighten someone’s world

Words are powerful remedies. Sometimes just the right ones at the right time can spark a feeling of relief or connection. Your story about your ostomy journey may touch someone going through the same experience. It could give them a sense of hope and helpful ideas. In this issue of Hollister Secure Start Services eNewsletter, Erica Henrickson shared her 5-year-old daughter’s story of triumph of living a full life after double ostomy surgery. Is yours the next story we feature?

Have you...

- Taken up a new hobby or sport since ostomy surgery?
- Attended an ostomy community event that changed your perspective?
- Found new ways to share your ostomy experience?

Submit your story today at

securestartnewsletter@hollister.com

Hollister Secure Start Services

eNewsletter

Resources

Hollister Secure Start Services

1.888.808.7456

www.securestartservices.com

Hollister Facebook Page 

United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826

info@uoaa.org

www.ostomy.org

Crohn's & Colitis Foundation

1.800.932.2423

www.crohnscolitisfoundation.org

Colon Cancer Coalition (CCC)

952.378.1237

www.coloncancercoalition.org

Bladder Cancer Advocacy Network (BCAN)

888.901.2226

www.bcan.org

Friends of Ostomates Worldwide-USA

www.fowusa.org

Youth Rally

www.youthrally.org

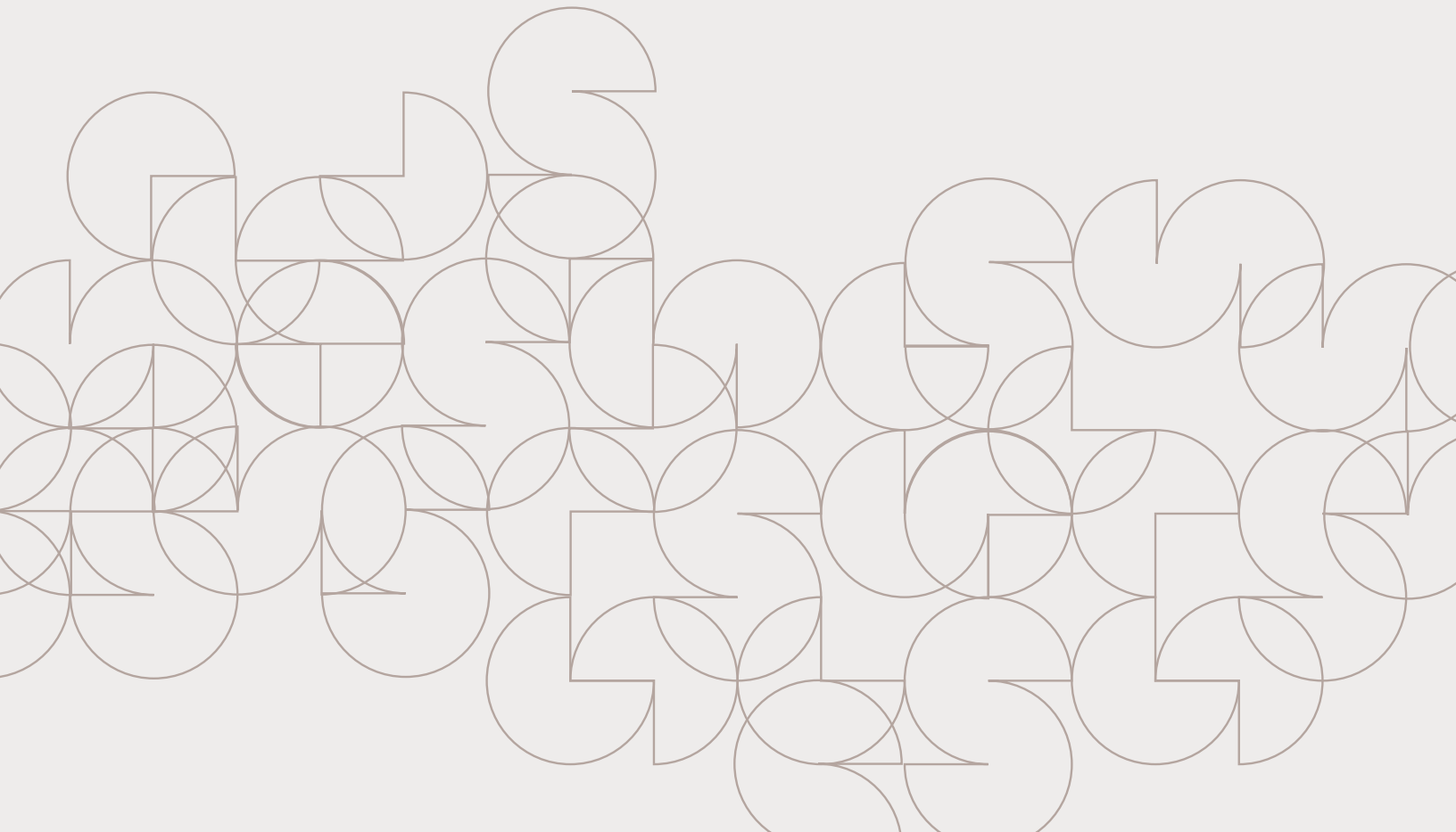
Run For Resilience

www.ostomy5k.org

Shadow Buddies Foundation

www.shadowbuddies.org

Click [here](#) to download past issues of the Hollister Secure Start services eNewsletter.





Secure Start™

It's Personal

We are proud to offer dedicated support for each and every ostomy and continence care patient along the continuum of care. Hollister Secure Start services provide a lifetime of personalized support.



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