Hollister Secure Start Services eNewsletter

Q3 2017

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Queen of the Road

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FEATURE STORY

Queen of the Road

Cheryl White is no longer afraid of the journey ahead

With the open road stretching for miles ahead and the wind in her hair, Cheryl White is in her glory. While riding her motorcycle, the past melts away and anything is possible.

"It gets my mind off of everything," says Cheryl. "It's a thrill beyond anything I've experienced."

Passing her on the road, no one would ever know that this attractive 60-year-old from Dobson, North Carolina, has an ileostomy or could ever imagine her life's bumpy journey. It began when her mother passed away from advanced colon cancer. Doctors tested the entire family and discovered that Cheryl has Familial Adenomatous Polyposis (FAP), which led to the removal of part of her colon at age 18. In the ensuing months, polyps multiplied resulting in several surgeries and finally an ileostomy at age 27.

Cheryl took her longest ride, to Georgia, in 2017



FEATURE STORY

Queen of the Road

(continued)

Cheryl originally didn't want to go through with the surgery, but after hours of library research, talking to her pastor and praying, she decided it was the right thing to do.

"My mom's death really saved my life," explains Cheryl. "Though she was given an ostomy, it was too late because her cancer was too advanced. I was fortunate that an ostomy would work for me—I knew I had to do it."

Cheryl and her husband lived on a farm that raises tobacco, corn and wheat. Before her ileostomy she could do anything the men could, including lifting a 50-pound bag of fertilizer. But afterward she was required to take it easy, which was difficult for her husband to handle, and the marriage eventually fell apart.

"I knew I could do it better on my own," says Cheryl. "It was rough, but I got through it."

It was this can-do attitude that kept her going even after a second failed

marriage and five surgeries due to blockages and an obstruction. The road finally got smoother when she met her fiancé Jack—her rock.

"He has been my biggest supporter; whenever I'm sick he's right beside me in the hospital," says Cheryl. "He told me I don't have to go at it alone anymore."

The two spent hours riding together on his bike, but Cheryl was hesitant to try it on her own because of her ostomy. Then one day Jack found a Honda 200 at a yard sale, fixed it up in Cheryl's garage and replaced the kick-starter with a battery to make it easier for her.

He taught her to ride, and she'll never forget the chilly day in December when she got her motorcycle license.

"I was fortunate that an ostomy would work for me—I knew I had to do it." -Cheryl White

"I was so excited that I insisted we go out on the highway in spite of the cold weather," chuckled Cheryl. "So we wrapped ourselves up and there we went!"

Due to a serious vitamin deficiency, Cheryl has to do infusions three times a week through a PORT-A-CATH system, but that doesn't keep Jack and her from their adventures. Jack has traded up to a Honda 1300 VTX

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Top: Cheryl in 2012 on the parkway

Bottom: Participating in a 2013 benefit ride

Queen of the Road

(continued)

and pulls Cheryl's ostomy supplies and infusions behind him in a trailer. With his love riding beside him on her new Honda Shadow 600, the world is their playground. They've ridden from North Carolina to West Virginia several times, but their longest trip was to Georgia this past April.

According to Cheryl, the key is to stay hydrated, take a lot of bathroom breaks, stretch and rest when necessary. She exercises at least five times a week on a treadmill, an elliptical and a small trampoline.

"Right now, I'm the healthiest I've ever been because I choose to eat well, exercise and I have someone who loves me," says Cheryl.

The road ahead is now clear. Cheryl plans on doing more to support others going through ostomy surgery. She remembers when a woman wearing a tight skirt came to see her in the hospital. Cheryl couldn't believe she had an ostomy and looked that good!

"If what I saw in that lady, people could see in me," explains Cheryl. "I could help so many people."

She had the chance when a friend asked her to speak to a young woman who was against having surgery. When they met, she looked Cheryl up and down and couldn't believe she had an ostomy. They spoke for an hour, and thanks to Cheryl's words of encouragement she decided to go for it.

Now Cheryl knows how important it is to share her story as often as possible, because when two paths converge the real healing begins. No matter the arduous journey, with someone who has gone before you cheering you on-anything is possible.

"I would have never dreamed in a million years that I would ride a motorcycle with my ostomy," concludes Cheryl. "Now I just put on my tight jeans and go!"

If you have questions about Cheryl's story, email us at securestartnewsletter@hollister.com



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

NEWS FROM HOLLISTER

Hollister Secure Start Corner

Meet the smile behind the voice

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

Wendi

Title:Consumer Service AdvisorLength of Service:3 months



How do you relax after a hard day of work? By playing with my kids. What's something you've been meaning to try but just haven't gotten around to it? Zip lining!

What is the most impressive thing you know how to do? Be a super calm Mommy of two even when things get hairy.

Nicole



Title:Consumer Service AdvisorLength of Service:8 months

How do you relax after a hard day of work? With a glass of wine and a good movie!

What's something you've been meaning to try but just haven't gotten around to it? I have been wanting to learn how to wakeboard and kneeboard.

What is the most impressive thing you know how to do? I can eat a pint of Ben & Jerry's ice cream in one sitting!

Ryan

Title:Supervisor, Consumer ServicesLength of Service:7 years

How do you relax after a hard day of work? By playing with my 10-month-old son, Jake, and my dog, Moose.

What's something you've been meaning to try but just haven't gotten around to it? Traveling to Europe ... hopefully someday soon!

What movie title best describes your life? Once Upon a Time in America.

MAKING A DIFFERENCE WITH MANNY

Fabrics to Help You and Your Ostomy Stay in Fashion

Fashion designer Manny Cuevas shares his custom-made advice

Here in "Music City", Nashville, Tennessee, we are consistently facing the wonderful challenges of "what and when to wear it out." And with Ostomy Awareness Day fast approaching in October, we want everyone to be well prepared for all the activities, especially those involving time outdoors.

I am particularly excited that the United Ostomy Associations of America's Run for Resilience is happening so close to me in Cookeville, Tennessee, on October 7. Whether you are running or not, here are some tips on what fabrics to choose from based on your personal lifestyle.

You'd be surprised what certain blends of fabrics can allow you to do. Cotton is the first on my list because it is a natural fabric that will hold more weight in moisture. Bamboo is also a natural fabric that allows you to breathe comfortably and feels soft to the touch. Tencel fabric, a sturdy, biodegradable textile made from wood pulp and also breathable, is soft to the touch as well.

Though not natural, GORE-TEX fabric is a synthetic material widely used in a large variety of outdoor apparel and gear. The microporous structure of the membrane enables garments to be waterproof and windproof. Also a synthetic fabric, nylon is found in many kinds of sports apparel, thanks to its capability to stretch and recover. The most popular synthetic fabric in use today is polyester. Found in clothing from activewear to children's pajamas, polyester is actually plastic! It's lightweight and breathable, but its drawback is that it holds onto odors and can foster bacteria growth. On the other hand, polypropylene is also made from plastic, however unlike polyester this synthetic material is water-resistant. Spandex fabric is another synthetic textile that has great expandability, is breathable and dries quickly.

Now that fall is here and winter is coming... Wool is a great option—from well-tailored duds to outerwear, wool is a natural! Great for keeping the body warm when needed, this favorite is still very breathable. Wool also doesn't retain odors like polyester does.

And last but not least, X-STATIC fabric is one of my favorites. It contains silver... yes silver! The metal that is woven into the fabric is a unique feature that acts as an antimicrobial to prevent bacterial and fungal growth after being worn. There are few brands that use this material in their products because of the higher price, but it's well worth it!

Here's to Ostomy Awareness Day and seeing everyone "Wear it Out" functionally and fashionably this fall.

Respectfully, Maunif

Experience Manny's legendary couture on Facebook@WearltOutbyManny or his website WearltOutbyManny.com.

Financial Disclosure: Manny Cuevas received compensation from Hollister Incorporated for his contribution to this eNewsletter.

ASK THE EXPERT

Transition Smoothly

Get back to living your life with these helpful tips

by Wil Walker, MBA, BSN, RN, WOC Nurse Manager, Clinical Education, Hollister Incorporated

Ostomy surgery is often a life-saving measure, but it is also life changing at first. Questions may arise about easing back into your normal routine whether at home or work. Know that you are not alone, and use the following tips to make your transition as smooth as possible.

I had my surgery three months ago, and I find myself constantly worrying about my stoma. Is this normal and will it pass?

During the first weeks and months after your surgery, you will be learning about your stoma and how to manage your "new normal." For most people, this phase will pass once you get used to the idea of having a stoma. The most important thing to remember is that you are in control of the management of your health and well-being. You are also not alone. Your Wound, Ostomy and Continence (WOC) nurse can help you. Support is also available from **Hollister Incorporated Secure Start Services**.

My grandson is six years old and very bright. He was upset when he heard I was having surgery and keeps asking me questions. How do I explain my condition to him?

Young children may want to know why you have to have surgery. It's good to be prepared ahead of time and anticipate some of these questions. How much or how little you decide to tell your children or grandchildren may depend on the nature of your family as well as the age of the child. Honest and simple explanations are important and help form the basis of good relationships with younger family members. There are a variety of ostomy-related resources available to you, such as books and dolls that can help you answer some of these questions.

I'm concerned that my ostomy will change the great relationship I have with my fiancé. How much should I tell him?

Questions from your relatives and friends are likely inevitable because they are concerned about your well-being. There is no need to go into detail unless you choose to do so. You may consider satisfying curiosity by explaining that you had a serious illness that became a threat to your health. Because of this illness, you had a major surgery and now wear an ostomy pouch. You could also offer more details when you are contemplating or have been involved in a sexual relationship. In either case, your stoma will not remain invisible and you will want to be prepared to talk about it. Check out our guide **Living with an Ostomy: Sex and Parenthood** for more information and recommendations.

I had my surgery three months ago and find myself crying a lot. Where can I turn for emotional support? If you are not making emotional progress and this is affecting your quality of life, then you should consider talking with your healthcare professional or a support group like the United Ostomy Associations of America.

Is it important to teach someone else in my family how to change and empty my pouch?

Your stoma is part of your life. It is also part of your family's and your partner's life. Some people find it useful if their family members know how to change and empty their pouch in an emergency. Explaining the details of your stoma care to those close to you can be great for your relationships and your peace of mind.

ASK THE EXPERT

Transition Smoothly

(continued)

I am an accountant and anxious to get back to work. How long should I wait after surgery?

You will need to decide when you are ready to return to work after your surgery. The time for this varies from person to person. The severity of the disease, the reason for your surgery, your recovery time, age and the type of job you do affects how long it will take you to get back to work. It is best to discuss returning to work with your healthcare professional. It's important to remember— try not to rush going back to work, if possible. Take your time. Going back to work before you are ready may cause more problems in the long run.

Feeling tired can be a real problem, even months after your operation. If you are experiencing low energy, it may help to know that this can happen to almost anyone. If it is an option, you may want to return gradually, perhaps by working part-time before going back full-time.

What should I bring with me when I go back to work to make things easier?

Carry a change of supplies with you in the car or in your work bag. Do not leave your products in a car during heat or extreme cold. Also, keep a change of supplies in your desk drawer or locker at work.



My job involves a lot of bending and stretching and I'm worried about injuring my stoma. Do you have any advice?

If you have a job that calls for a lot of bending and stretching, two useful things can help. First, wear a pouch that can be attached to a stoma belt for added security while you are working. Second, wear loose-fitting clothing and avoid constrictive belts and tight trousers.

I work outdoors as a foreman and though I don't do a lot of heavy lifting, I tend to perspire a lot. What can I do to make sure my pouching system stays in place? If your job is fairly active, you may perspire at the area where the pouch is attached to the skin. This can be particularly frustrating because sweat and/or oily skin can reduce the effectiveness of the adhesive holding your pouch in place. You may need to change your pouch more often. An option is to use a skin barrier that copes better with perspiration. Your WOC nurse or your supplier can provide recommendations.

What should I consider when choosing a supplier for my pouching system and accessories?

Once you have established a product fit that is right for you, it is time to find a supplier that can provide you with an ongoing supply of ostomy products. There are several considerations when choosing a supplier:

- Do you want to work with a national or regional durable medical equipment (DME) supplier who can mail your supplies, or do you prefer to pick up supplies at a local pharmacy or DME supplier?
- Can the supplier bill your insurance in-network to minimize your out-of-pocket expenses?
- Do you already have a DME supplier that serves your other medical device needs?

Many ostomy supplies are covered by private insurance plans, military benefits, Medicare and Medicaid. Check with your carrier to find out your level of coverage and if you must use a specific supplier.

Have a question that wasn't answered here? Check out this helpful new brochure from Hollister Incorporated. Living with an Ostomy: Home & Work Life

Hollister Secure Start services is here to help! We can help answer your questions about your return to work and/or getting back to your normal activities. Call us today at **1.888.808.7456**.

EVENT UPDATES

Meet Us at the Starting Line

The Run for Resilience Ostomy 5K celebrates four years of family and fun

Ostomy Awareness Day is October 7 and the excitement is building at United Ostomy Associations of America (UOAA). This year's theme is "Navigating the Journey Together" to recognize those who have supported people with ostomies along the way. For the fourth year in a row, UOAA will sponsor the Run for Resilience Ostomy 5K and our team at Hollister Incorporated will be right beside them as a platinum sponsor of the event.

Back in 2014 when Wound, Ostomy and Continence (WOC) nurses, Lara Leininger and Angela Richardson, launched the inaugural WannaWearOne Ostomy AWEARness 5K race in Durham, North Carolina, they couldn't have imagined how big it would become four years later. Though the name changed last year to Run for Resilience Ostomy 5K, the goal is the same—to raise ostomy awareness.

This year, the Run for Resilience Ostomy 5K events will take place in Durham, North Carolina; Birmingham, Alabama; Portland, Oregon; Boise, Idaho; Cookeville, Tennessee; and Mesa, Arizona.

"It's the local organizers who have the passion to make these events a success," says Ed Pfueller, Communications Manager, UOAA.





The excitement will also spread from coast to coast as people run or walk the free Nationwide Virtual Ostomy 5K. Participants receive an official race bib and are encouraged to fundraise using the UOAA site.

"We want everyone to know that if they can't make it to an event they can still walk or run at a local park or even on a treadmill to raise donations and awareness," explains Ed.

Much more than a walk/run, the Run for Resilience has become a family-friendly event that participants look forward to all year. At some of the events, parents with infants and toddlers run in the stroller-division, and kids flock to a special 50-meter dash—complete with awards! The Durham event offers face painting, games and coloring books. Mascots and players from local sports teams often show up. Last year a robust silent auction raised over \$2,000 thanks to donations from local businesses and restaurants!

Of course the main focus is the run. It attracts avid runners as well as people with ostomies who have their own race division.

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Above: The kids are off and running at the 2016 Boise event

Left: Wool E. Bull makes an appearance at the 2016 Durham event



EVENT UPDATES

Meet Us at the Starting Line

(continued)

"It was so exciting that a race participant with an ostomy came in first," says Lara Leininger, Co-Race Director and Co-Founder of the Run for Resilience. "Having an ostomy doesn't have to limit you."

To raise awareness, mile markers with ostomy facts pepper the routes. Runners get a bag packed with educational materials, as well as pouches as educational tools for non-ostomates at the races.

Some of the runners form teams of co-workers, friends or family members and solicit donations which go directly to support UOAA.

Ultimately, the Run for Resilience changes lives. Megan Herrett, Race Director in Boise, Idaho, and her husband have two children with ostomies. Phillip Moyle of the UOAA support group in Spokane, Washington, has had an ileostomy for over 30 years and traveled to their event. He wrote to UOAA:

"The Herrett Family journey and the ways that Megan and Matt handle their lives, as well as their children's by openly reaching out to and engaging with the community is very inspiring to me, and encouraged me to change how I interact with my family, friends and community."

Phillip's epiphany is just one among many that have occurred thanks to the Run for Resilience and the efforts of UOAA. Yours just might be next! Ostomy Awareness Day is just around the corner, so make sure to go to **ostomy5k.org** to either participate in an event or do your own virtual walk or run. Either way, you will be helping raise ostomy awareness.

2017 Run for Resilience Events "Navigating the Journey Together"

October 7

Durham, NC Cookeville, TN Mesa, AZ Virtual Ostomy 5K—National!

October 14

Birmingham, AL Boise, ID Portland, OR—Fun Run

To register, visit ostomy5k.org





We've Only Just Begun

At Hollister Secure Start services, we are committed to supporting you throughout your ostomy journey, not just right after surgery. We want to be there for you weeks, months and even years from now. As time passes your needs may change, and we are here to support you with everything from help choosing products to answering all your questions. Click on the link below and share your contact information so we can update our records and continue to support you. It only takes a few moments—for a lifetime of personalized care.



WHAT'S SO FUNNY?

Why Only One Day?

Brenda celebrates Ostomy Awareness every day with comedy and connection



Ostomy Awareness Day is October 7 and my question is "Why only one day?" Ever since I found out I would need an ostomy, every day has been an "Ostomy Awareness Day" for me. I'm sure many others who live with ostomies feel the same way; it's kind of hard to escape.

When I was diagnosed with colorectal cancer in 1995, at age 39, I was a busy hair-salon owner, mother of two young children and a wife. On the day the doctor told us that I would need a permanent colostomy, I was dumbfounded like most people. When I realized it would save my life and I'd have a chance to see the kids grow up, I told the doctor, "Bring on the Bag!" The colostomy was a lifesaver, and in the process of going through cancer and ending up with an ostomy, many new opportunities came my way.

"If I can convince people to get their colonoscopies my mission is fulfilled."

–Brenda

It never occurred to me to be ashamed of having an ostomy. I was grateful there was a solution to my problem and thought it was a small price to pay. Has it been easy? Not always, it's been darn right messy at times!

Why Only One Day?

(continued)

I made a decision early on to educate my clients at the salon about the importance of colonoscopies, and I have never stopped. These days I talk to large audiences instead of one on one. I am even in a PSA commercial about colonoscopies that plays every March on several stations in Minnesota. One morning a TSA officer said to me, "Didn't I see you on TV today?" Another time, I was in Target shopping and the cashier asked me the same thing. But the funniest time was in a car with several writers who I'd never met before. We all ended up talking about our books and when I mentioned bowels and ostomies. one of them said, "Have you seen that funny commercial with the comedian talking about her butt?" My friend said, "You're sitting next to her!" You can see it on my website at livingandlaughing.com. That's enough fame for me! If I can convince people to get their colonoscopies my mission is fulfilled.

On my one-year anniversary of finding out I had cancer, I was working late in my hair salon when my father called to say, "Do you remember what happened a year ago on this day?" "Yes, I do, I was just thinking about that," I said. I was glad it was acknowledged, and then regretted not planning something special to celebrate. Just then I heard music outside. It was two men in full Scottish regalia practicing their bagpipes. I invited them in from the cold to practice in my hair salon. My regrets left as they played, "Amazing Grace" and went on their way. On the actual one-year anniversary of my colostomy surgery, October

24, I decided to call my dad. "Hi Dad, do you know what happened one year ago today?" "Nope, what?" he asked. "It was the last time I wiped my butt!" We both had a laugh about yet another advantage of ostomy surgery.

This Ostomy Awareness Day, there will be Run for Resilience Ostomy 5K races around the country. I personally know how crucial it is to raise ostomy awareness. I've written books about it, talked in front of crowds large and small, and have been interviewed for papers and TV countless times.

For twenty years now I have been spreading awareness about ostomies and their importance. Not only do they enhance the lives of people with bowel diseases, but also save the lives of those with cancers and other reasons bowels go berserk.

We, the people with ostomies, should celebrate each day, even with skin issues, pouch problems and self-esteem challenges. Many people do well with their ostomies and carry on with all the fun things they did before they had it. We are grateful every day for ostomy awareness. It means we're still living, loving and laughing. What else do we need? Okay, a good pouch system always helps.



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.

EVENT UPDATES

Growing Stronger

San Diego hosted a record-breaking Youth Rally 2017





Youth Rally 2017 medical education, fitness class and group photo

This year's Youth Rally held at San Diego State University, July 17-22, hosted 155 campers and 82 volunteers including nurses, counselors and administrative assistants—the largest number to date!

Youth Rally is a transformational camp that provides a non-threatening environment for young people ages 11 to 17 with any sort of bowel or bladder dysfunction. The ultimate goal of the camp is to encourage selfconfidence and independent living, and it's done with a mixture of all-out fun, connection and education.

"At Hollister Incorporated, we were proud to be a sponsor," said Heather Budorick, a certified Wound Ostomy Care Nurse (WOCN) and Clinical Specialist at Hollister Incorporated, who was also on hand to answer questions and assist campers as needed.

Most of the counselors were once campers themselves and acted as invaluable role models. Each camper attended a break-out session with others their own age, facilitated by counselors. For many, it was the first time they met other kids in the same situation as them.



Growing Stronger

(continued)

The peer-to-peer experience is life changing. For example, some of the campers had not gone swimming since their surgeries but the pool on campus was a big hit. At first some kids would go in to the water wearing big shirts to cover up their pouches. But once they saw others wearing swimsuits, they followed suit, unashamed of a telltale pouch or scar.

Inspiring as well was a presentation by Nick Scott, the founder of Wheelchair Bodybuilding, Inc. and two-time World Power Lifting Champion. Nick became paralyzed at age 16 after a car accident and uses a wheelchair. He motivated campers with his story and let them know that whatever happens in their lives—they have control of their destiny.

"If I can do it, anyone can achieve their goals."

-Nick Scott

The event was jam-packed with fun activities like trips to Mission Bay, the beach and Old Town San Diego, but campers loved taking the spotlight in a fashion and talent show. There was also a closing night dance, held outdoors for the first time in Youth Rally history.

Youth Rally 2017 fulfilled many dreams for campers, whether it was swimming for the first time, finding a lifelong friend or finally knowing they were not alone. And best of all, they can't wait to come back next year!

Mark your calendars for Youth Rally 2018 on July 16-20 at the University of Colorado in Boulder, Colorado. Know a young person who would benefit from this life-changing experience? Go to **youthrally.org**.

Youth Rally 2017 campers enjoy Mission Bay

What's Your Story?

Sharing it may just change someone's life!

Though we all share the ostomy experience in one way or another, each one of us is unique. We'd love to hear your personal story. There just might be someone who needs to hear it too. Cheryl White shared her story in this issue of the Hollister Secure Start Services eNewsletter yours could be next!

Have you...

- Done something you never thought you could?
- Found new inspiration?
- Made a difference in the ostomy community?

Share your story with us. We just might profile you in one of our upcoming eNewsletters because your story matters!

Submit your story today at **securestartnewsletter@hollister.com**.



"Owning our story and loving ourselves through the process is the bravest thing we will ever do."

-Dr. Brené Brown



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Resources

Hollister Secure Start Services

1.888.808.7456 www.securestartservices.com Hollister Secure Start Facebook Page **(**)

United Ostomy Associations of America, Inc.

(UOAA) 1.800.826.0826 info@uoaa.org www.ostomy.org

Crohn's & Colitis Foundation of America, Inc. (CCFA) 1.800.932.2423

www.ccfa.org

Inspire.com Ostomy Support Group

www.inspire.com/groups/ostomy

Colon Cancer Coalition (CCC)

952.378.1237 info@coloncancercoalition.org www.coloncancercoalition.org

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Secure Start[™]

It's Personal

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