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eNewsletter



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Feature StoryOstomy Is In Fashion

FEATURE STORY

Ostomy Is In Fashion

Manny Cuevas puts heart, soul and guts into modern couture

From headlining New York's Fashion Week to near death in a Nashville hospital, Manny Cuevas knows the highs and lows of life. The son of famous costume designer Manuel Cuevas, Manny Jr. became fascinated with scraps of leather and shiny fabric remnants in his father's studio as a boy. He began sewing at the age of six and rose to international fashion fame with his opulent, pop culture couture line — "Wear It Out by Manny."

The seesaw of his life swung downward the morning of May 12, 2012 when, after a creative morning in his East Nashville studio, he experienced a bad cramp. Things went from bad to worse, and his pregnant partner, Lora, convinced him to go to the emergency room. It wasn't until five days later that doctors told him that the attempts to reduce an intestinal blockage had failed and he'd have to have surgery to save his life.

"My life seemed to be flashing by in an instant. I was now extremely scared, not only for myself, but also for my family and my work," explains Manny.

Eight hours later, he came out of intensive surgery with a colostomy. Manny's ostomy journey didn't stop there, but veered alarmingly off track with countless infections, a consequent ileostomy and a surgically damaged kidney. In May of 2013, the gifted designer closed his studio due to expenses, pain and exhaustion.

It wasn't until Manny found Dr. Richard Miller at Vanderbilt University Medical Center that the seesaw began to rise. The doctor diagnosed him with internal MRSA (Methicillin-resistant Staphylococcus aureus) and took him under his wing for care. After an attempt to surgically reconnect again in 2015, complications forced Dr. Miller to abort the surgery leaving Manny with a permanent ostomy. Nashville singer Paul

McDonald (singer for *The Grand Magnolias*), rockin' an old school, flower embroidered suit that was custommade by Manny (right), and worn on *American Idol*.

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"We've been picked because only the strong survive and with all of us together we can make a difference."

—Manny Cuevas

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FEATURE STORY

Ostomy Is In Fashion

(continued)

That's when the healing began to take place. A fashion designer is part artist, part craftsman, and Manny used all of his talents to piece his life together anew. Jeanne, Manny's ostomy nurse, aimed him in the right direction from the start.

"Her kindness and patience in teaching me how to maintain the ostomy was unbelievable. She eased my confusion and coached me in how to allow my whole body to work together," says Manny.

Early on after surgery, Jeanne took Manny to an ostomy support group meeting. Though many of the participants were much older than he, Manny was humbled by their honesty and felt comfortable to share. The irresistible charisma that made him so successful in his work had returned.

He said, "We've been picked because only the strong survive and with all of us together we can make a difference. Let's not forget that the most delightful thing in life is change."





Fashion by Wear It Out by Manny featured on the cover of *Cowgirl* Magazine, as well in an article entitled "Made for America".

He felt their smiles come from deep within, stemming from a sense of security and passion. It was then that Manny knew it was his calling to guide others through the darkness that he had experienced.

Of course there were challenges. His body dramatically changed after all of the surgeries and he became sensitive to adhesives. After trying every product on the shelf, he finally turned to Hollister Incorporated and found one that worked.

Furthermore, the placement of his stoma was smack dab at his waistline, preventing him from tucking in his beautifully designed shirts. He used this personal challenge to design clothing for people with ostomies. After bringing a few pieces to an ostomy fair to rave reviews, Manny is considering coming out with a full line.

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FEATURE STORY

Ostomy Is In Fashion

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"We need to feel as glamorous as we did before," says Manny. "It's another outlet for me to share my creativity and make people feel incredible again."

It was then that Manny knew it was his calling to guide others through the darkness that he had experienced.

Manny is more stable now and is excited to get back to his studio. He has a lot to be grateful for. In 2013, the Nashville music community got together to produce a benefit for their longtime friend to help defray medical costs and support him

in future endeavors. The "Wear It Well, Wear It Out" evening featured the Mavericks, as well as a whole host of other Nashville greats; many of whom were his clients.

"The willingness of people to do that for me made me cherish the great fullness of life, and know that everything would be OK," says Manny.

Ultimately, he credits Lora (who has been his rock) and three beautiful children for his recovery. While on the mend, Manny has taken on the role of a stay-athome dad. He can often be found in the bleachers cheering on his oldest daughter, Sofia, at her softball games. The seesaw of his life has definitely swung upward.

"This experience has taught me patience and brought me closer to my family and friends," concludes Manny. "Unexpected change can sometimes be a challenge, but you can overcome those challenges by allowing your spirit, mind and body to work together—but you have to believe!"

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





Under the Big Tent at New York Fashion Week



NEWS FROM HOLLISTER

Secure Start Corner

Meet the smile behind the voice

Our team of Lifetime Service Coordinators is passionate about helping Secure Start members over the phone or by email. If you have a question about your ostomy, they're here to help.



Coryn

Region:	Southeast
Title:	Lifetime Service Coordinator
Length of Service:	4 months

Favorite childhood memory: Playing with my aunt's makeup as a child.
If I could be a fictional character... I would be Dory, from *Finding Nemo*.
If I could have lunch with any three people: Pizza with Chelsea Handler, Ellen DeGeneres and Betty White.



Sianna

Region:West CoastTitle:Home Health CoordinatorLength of Service:3 months

Favorite childhood memory: Visiting Mackinac Island with my family.If I could be a fictional character... I would be Ariel from *The Little Mermaid*.If I could have lunch with any three people: Sushi with Ellen DeGeneres, Sofia Vergara and my dad.



Kevin

Region: Title: West Coast Acute Care Coordinator 3 years

Length of Service: 3 years

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Favorite childhood memory: Spending 2 weeks in Northern Wisconsin with my family every August.

If I could be a fictional character... I would be Zach Morris from *Saved by the Bell*—He can freeze time!

If I could have lunch with any three people: Deep-dish, Chicago-style pizza with my wife, Laura, and both of my grandfathers (who died when I was younger).

ASK THE EXPERT

Back-to-School 101

Study these tips for managing your ostomy in college

by Wil Walker, Manager, Clinical Education, Hollister Incorporated and Lynn Sacramento, Clinical Education Specialist, Hollister Incorporated

There are so many things to juggle when starting college, but even more so when a student has an ostomy. It's natural for questions to come up regarding dorm life, long classes and activities. The following are some frequently asked questions along with tips and advice.

Q: I am probably going to have classes across campus from my dorm and won't be able to get back to change my pouch. What should I keep in my backpack for emergencies?

A: We would suggest that you keep: one pouch/barrier (if it is a cut-to-fit option, have it already cut to your size if needed); a non-moisturized/non-oily wipe to clean the skin; and a disposable garbage bag to discard the used pouching system. Consider a closed-end pouch if you have stool drainage.

Q: Sometimes I am uncomfortable sitting in class all day. Is there any specific clothing or accessories that can provide more support?

A: Depending on the source of discomfort, some people may benefit from looser-fitting clothing that may have some stretch such as a dress or clothing with Lycra, like yoga pants. There are several manufacturers that offer support belts and undergarments that provide light support to minimize the weight of the pouch. Also, try to empty when the pouch is 1/3-1/2 full. A filtered pouch can help to minimize pouch inflation if gas is a concern.

Q: What should I eat in order to stay energized and healthy throughout the school year?

A: Hydration is essential. Make sure you drink plenty of water throughout the day. Visit

securestartservices.com/ostomycare for

informational materials targeted to each type of ostomy.



Refer to these for a list of foods that cause gas, diarrhea or constipation. Always consult your healthcare professional for recommendations on dieting.

Q: Are there any sports or physical activities I should stay away from?

A: Consult your physician before returning to sports or participating in a new sport. It will be important to protect your stoma from physical impact and injuries. There are stoma guards/protectors available for these situations.

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ASK THE EXPERT

Back-to-School 101

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Q: I am going to be sharing a bathroom with three roommates. Do you have any advice about how to make my ostomy-changing routine less conspicuous?

A: There are several products that will help to minimize odors such as a lubricating deodorant or deodorizing drops that can be put into a pouch if you have a colostomy or ileostomy. If you have a urostomy, there are products that can be used to clean out the bedside and leg bag collection system. Disposable individual garbage bags are available with some pouching systems that would allow you to discreetly dispose of the pouch. A garbage can with a lid will help to contain any odors and it's a good idea to place deodorizers inside. If you are comfortable to discuss this with your roommates, it may help them to have a better understanding of your situation. Find videos and literature on the Hollister Incorporated website (securestartservices.com/ostomycare) to share with your roommates so they can learn more about your specific



M9 Odor Eliminator

situation and needs.

Adapt Lubricating Deodorant

Q: Sometimes my ostomy makes noise during class. Is there a way to alleviate this?

A: If you place your hand over your pouch near your stoma this will help to minimize the noise. There are also manufacturers that make guards to minimize/suppress noise from the stoma.

Q: Do I need to tell my professors about my ostomy?

A: This is not required. The decision should be based on what will make you most comfortable. If you have a 3+ hour class and know that you will need to empty your pouch more frequently, you may choose to alert your professor about your needs.

Q: Are there any scholarships that students with an ostomy can apply for?

A: There can be many opportunities available for students with ostomies or related chronic illnesses. Research "scholarships for students with ostomy" online to investigate your options and find out more. Here are some resources to get you started:

Crohn's and Colitis Young Adult Facts Crohn's and Colitis Scholarship College Scholarships by Type of Disability

If you have any further questions about going back to school with an ostomy, please call your dedicated Secure Start coordinator at 1.888.808.7456.

EVENT UPDATES

Bouncing Back Into Life

Ostomy Awareness Day 2016 celebrates resilience

Anyone who has an ostomy or is close to someone with one knows the guts it takes to bounce back into day-to-day life after surgery. The United Ostomy Associations of America (UOAA) celebrates this fortitude on Ostomy Awareness Day—October 1, 2016, with the theme of "Resilience".

"We want to celebrate people who have found their resilience and support those on their journey as they discover it" explains Jay Pacitti, Executive Director of UOAA.

UOAA is taking to social media to celebrate the day with a photo campaign. Everyone is encouraged to take a photo holding a sign that reads "**#IAmResilient**" and post this hashtag to their social media accounts tagging UOAA. There will also be a live Twitter chat. More information can be found on UOAA's website—**ostomy.org**.



Individuals are also asked to communicate with their local media to spread awareness of the campaign and contact local or state officials to recognize the day with a proclamation.

Hollister Secure Start services is a proud sponsor of the Run for Resilience Ostomy 5K, the crown jewel

of Ostomy Awareness Day. Initially launched in 2014 by two dedicated WOC nurses in Durham, North Carolina as the WannaWearOne 5K, this event drew nearly 300 runners in 2015 in honor of World Ostomy Day.

The ultimate goal of the races is to educate, support and raise community awareness about people living with an ostomy. These family-friendly events have now grown from coast to coast and overseas. Interested in running the race but unable to physically attend the events? You can still sign up and run or walk your own virtual 5K race. Runners/walkers pay a registration fee and receive a T-shirt. Sponsorship support will offset event costs and all remaining proceeds benefit the United Ostomy Associations of America (UOAA). Here's a rundown of the Run for Resilience Ostomy 5K events planned for the month of October:

October 1: Durham, North Carolina October 1: Virtual 5K October 8: Boise, Idaho October 8: Birmingham, Alabama October 13: London, England October 15: Portland, Oregon To sign up or for more information go to ostomy5K.org.

UOAA is a national organization devoted to supporting and advocating for people who have had or who may have ostomy or continent diversion surgery.

A Gutsy Idea Meet Lois Fink, creator of the IBD & Ostomy Awareness Ribbon

Lois Fink struggled with Crohn's disease for 19 years, and it was only after ostomy surgery that

she realized she no longer felt the shame and embarrassment she had been wearing like a heavy lead cloak. She knew that she could start telling her story. Lois is now an inspirational speaker.

When the pink breast cancer ribbon became popular, Lois wondered why there wasn't a ribbon for inflammatory bowel disease (IBD) and ostomy awareness. She turned to her friend Barb Wodzin and said, "We have nothing to lose and I have a gut feeling this idea could take off."

Lois and Barb both agreed the ribbon had to be brown and collected various samples. Their first attempt at constructing a ribbon proved unsuccessful and they glued their fingers together! Then one day Barb called Lois and said, "I'm at the store and I see these tiny red jewels!" Of course this was the finishing touch they had been looking for a symbol for the stoma.

They started a Facebook page and there was demand for the ribbon from around the globe with requests from Canada, the Bahamas, the United Kingdom, New Zealand, Malta and the United States. Later the ribbon became sponsored by Get Your Guts in Gear. It has become synonymous with Ostomy Awareness Day and Lois can't be more surprised or happier.

Purchase your own IBD & Ostomy Awareness Ribbon at igotguts.org/ibdribbon.



EVENT UPDATES

Inspiration Goes to Camp

Youth Rally 2016 was life changing for all involved

We are proud to be a Gold Sponsor of the Youth Rally, a transformational summer camp that provides a safe environment for young people ages 11 to 17 with any sort of bowel or bladder dysfunction. This year's camp took place July 25th through 30th at the University of Washington, Seattle, and we experienced its magic firsthand through the eyes of Heather Budorick, one of the camp's volunteer registered nurses and a Clinical Specialist with Hollister Incorporated.

Excitement was in the air from day one as 128 campers and a staff of 80 including registered nurses, counselors and administrative assistants converged. The ultimate goal of the camp is to encourage self-confidence and independent living, and it's accomplished through a mixture of all-out fun, personal connections and education.

Inspiration is woven throughout the experience. For example, most of the counselors were once campers themselves and act as invaluable role models to the camp

attendees. On Friday, Jada Sheeler, world traveler and Spencer Kimbro, Team USA paralympic athlete motivated campers with their uplifting stories.

The biggest hit, especially for first year campers, was the Tuesday break out groups where attendees got the chance to talk with others in a similar situation. A counselor, who had the same or similar medical diagnosis as the campers in each group, facilitated the hour-long sessions. As a Certified Wound Ostomy Care Nurse (CWOCN), Heather answered and clarified any medical questions that came up.

"Mostly the campers explained their experiences and some had concerns that are very understandable for a person caught between childhood and adulthood," said Heather.

Fun ensued as well, with a field trip for boating and swimming to Green Lake Park; Wacky Wear Bowling Party, Lip-Sync Battle, talent show and an Under the Sea themed dance.

The ultimate goal of the camp is to encourage self-confidence and independent living.

2017 Youth Rally July 17th – July 22nd San Diego, California We look forward to being involved again. Know a young person who would benefit from this life-changing experience?

Go to www.youthrally.org.





EVENT UPDATES

Upcoming Webinar Opportunity

Please Join Us September 14, 4:00 pm CT

Are you curious about how the fit + formulation of your ostomy pouching system contributes to maintaining healthy peristomal skin and would you like to learn more about your options?

In collaboration with **Inspire.com**, Secure Start services presents a new webinar: **Fit + Formulation**. Join our ostomy product experts Rachael and Mike, September 14th at 4:00 pm CT, as they discuss how finding the right pouching system fit can help you stay healthy. Register for the event by **clicking here**. Or call us today to learn more at 1.888.808.7456.

The Fit + Formulation Story



Inspire.com is the leading social network for health. In partnership with more than 100 nonprofit patient advocacy organizations, Inspire creates and manages health-condition-specific support groups for some 850,000 patients and caregivers.

Girls With Guts Retreat September 30 – October 3 Stroudsburg, Pennsylvania

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

Get Your Rear in Gear® *Multiple Dates 300 Events in 32 states*

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

WHAT'S SO FUNNY?

Bikini Envy

Brenda uses humor to let her empowerment hang out

All you have to do is go to the UOAA National conference to see some major empowerment going on there. One of the biggest changes I've noticed over the last 10 years is the young people displaying their pouches as they walk through the hotel to the pool. No more embarrassment or hiding them. It has to be liberating! Now the day that I parade around in a swimsuit, I don't know if I'd call that liberating more like my inevitable dementia has finally kicked in. Strolling around in my bathing suit would definitely take me out of my happy place. I'd rather lift my shirt and show off my ostomy in the *New York Times* instead! Trust me when I tell you me in a bikini would not be how to win friends and influence people!

I've been blessed with the opportunity to interview hundreds of people for various topics in my books. People have shared stories about camping, intimate moments, accidents, how to tell someone about their ostomy, and being able to laugh at themselves. With each person I learned what empowers people in the ostomy world. Walking into my first ostomy support meeting in Minnesota, I learned I wasn't alone; in fact, my ostomy wasn't the star, either. One person talked about how, prior to surgery, they knew where every bathroom was within a five-mile radius, and



Brenda reading from one of her books at the UOAA conference.

now could make it through an entire movie, dinner or social engagement without worrying anymore. They were empowered to have their lives back with less pain and drama.

I thought I would be meeting a bunch of sad, smelly people, but instead was greeted with a laughing, good-looking, non-odorous bunch who greeted me with

open arms and encouraged me to know everything would be okay. I needed that assurance after watching stool propel out of my abdomen and all over my bathroom sink, counter and floor that day. Hope and humor were the medicine I needed and the isolation ended immediately.



Brenda Elsagher

I didn't set out to be a speaker, comic or writer, but having a colostomy and not being ashamed of it, gave me a sense of empowerment too. If I can make a difference to the general population that will get them to get a colonoscopy, my job is done. If I can make a difference with someone struggling in the ostomy world for the first time, that's a bonus! We all have trials, but how we choose to face them defines us going forward. I decided to use humor as my coping technique and it's worked for me. I've had awesome experiences meeting people with ostomies across the country. I love trying new things and challenges. It still doesn't mean I'm going to purchase a bikini anytime soon.

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**

NEWS FROM HOLLISTER

Welcome to Secure Start Services



As a member of Secure Start services, you're not alone. You may have questions about your ostomy, how to care for your stoma, and how to keep on living the life you want to live – but you don't have to figure it out on your own. At Secure Start services, we are proud to offer complimentary dedicated support for as long as you need it, regardless of the brand of products you use. Here's just a few ways we can help:

- Finding the right product fit
- Helping you sort out your insurance coverage
- Identifying supplier options
- Accessing an ostomy nurse over the phone to find answers to your clinical product questions
- Providing product information and condition-specific education
- Finding local resources

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

Survey Results

Thanks for sharing!

In our last issue we shared a link to a 60-second survey to help us better understand what you love about the Secure Start eNewsletter and what we can offer in the future. Thanks to everyone who responded! We heard that you most enjoy the News From Hollister and the Feature Story sections of the newsletter, so expect more of what you love in the next issue. When it comes to future topics, you shared your interest in reading more testimonials from real people and links to educational resources. We are happy to oblige and look forward to sharing more details and more ways to interact with you in the coming months.

As always, thanks for sharing with us and allowing us to serve you!



Secure Start eNewsletter Resources

Secure Start Services 1.888.808.7456 www.securestartservices.com Secure Start Facebook Page (f)

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 www.inspire.com

To download past issues of Secure Start eNewsletter, click here.

Share Your Story

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



It's Personal.

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