Hollister Secure Start Services eNewsletter

Q2 2017

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Feature Story Turning the Tide

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FEATURE STORY

Turning the Tide

Missy Padgett swims in the healing waters of caregiving

Malisa (also known as Missy) Padgett of South Carolina has worked in the medical field since 2006 and has been a National Registered Medical Assistant since 2012. But after her ileostomy surgery in 2013 and a total proctocolectomy in 2014, she wondered if she would be able to continue to heal others.

"I thought everything I loved and used to do would be gone," says Missy.

This 43-year-old caregiver has battled Crohn's disease since 1999 as well as kidney cancer. She also lost her dad from a massive heart attack during this very overwhelming time.

The unconditional support of her family, friends and strong faith helped her through the tsunami of emotions, but she had no idea how to connect with the ostomy community. She learned how to change her pouching system by herself and affectionately named her stoma "Violet" after the character in her favorite movie, *Willy Wonka and the Chocolate Factory* (the Gene Wilder version).

As she pushed through, the tide began to turn. She eventually found various support groups on Facebook where she met kindred spirits.

"After talking to others, I knew I would either have to accept Violet or stay in bed under the covers," explains Missy.

(continued on the next page)

"You only live once, and I just want to keep living." -Missy Padgett

FEATURE STORY

Turning the Tide

(continued)

She went to a United Ostomy Associations of America (UOAA) National Conference in 2015 and learned new ways to cope with her ileostomy. She then found a new way to use her caregiving skills—as a Committee Member of the 30+ Network, a virtual peer mentoring support group affilated with the UOAA for people over age 30.

"It's very rewarding for me to help bring people together with the same issues and offer support," says Missy. "It gives me the sense of security that I will never walk alone."

"I told myself I wasn't going to let my stoma own me, I was going to own it." <u>–Missy Padgett</u>

Due to the recovery process after surgery, Missy had to quit her full-time job. But not one to take it easy, she longed to get back into the medical field. Twoand-a-half years later she got a part-time job in home healthcare assisting patients after surgery, checking



Missy at the 2015 UOAA Conference

vitals and administering medications to young and old. "Just making people feel better puts a huge smile on my face," says Missy.

Though pain swells from time to time, it doesn't stop Missy from walking, doing Pilates and lifting weights. She wears the New Image two-piece pouching system from Hollister Incorporated and a stretchy abdominal band to protect Violet.



As a self-proclaimed beach fanatic, she's back to one of her favorite places on earth—the beach. She now has the confidence to strut her stuff and not worry about what people think about her ostomy.

In her downtime, she spends time with her friends, family and boyfriend (the love of her life) of seventeen years who stuck by her throughout her illness. "My ostomy doesn't bother him," says Missy. "Even though I look like I've been through a paper shredder, my scars tell a story like tattoos do."

Her new story is just beginning. The next chapter of her adventure includes skydiving and traveling (since her boyfriend works for an airline). There are even whispers of getting married in the future! Missy looks forward to it all.

"You only live once, and I just want to keep living," says Missy.

Financial Disclosure: Malisa Padgett 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.

Rachael



Title:Consumer Service AdvisorLength of Service:18 months

First phone app you check in the morning? I open up "Disney's Magic Timer." The app rewards my son with virtual stickers every time he brushes his teeth. It plays catchy music—we dance and brush carefully!

What's your summertime guilty pleasure? Trips to our local amusement park. Always fun until you find yourself in a 40-minute line.

What is your favorite summer meal? We always have plenty of homegrown vegetables. Cucumber, tomato and basil salad is the best summer meal paired with a huge turkey leg.

Taylor



Title:Consumer Service AdvisorLength of Service:6 months

First phone app you check in the morning? My text message app and, after that, Facebook.

What's your summertime guilty pleasure? Going out for ice cream at Tastee Freez.What is your favorite summer meal? Favorite meal during summer is anything cooked on the grill.

Emily

Title:Consumer Service AdvisorLength of Service:3 years

First phone app you check in the morning? Twitter. I like being able to see what is going on in the world before I start my morning.

What's your summertime guilty pleasure? In the summer I love going to country music concerts and spending time with my family and friends.

What is your favorite summer meal? I love eating fresh vegetables and herbs from my garden in the summer and, of course, I can't go without watermelon!

MAKING A DIFFERENCE WITH MANNY

Ostomy is in Fashion

Fashion designer Manny Cuevas shares his custom-made advice



I am honored and humbled to be invited as a regular contributor to the Hollister Secure Start Services eNewsletter for 2017! While sharing some fashion tips and secrets, I will provide insights and revelations that will cover some of the challenges we encounter every day as part of this grand family of people with ostomies. I hope to encourage you to fulfill your dreams while living with this condition, that's invisible to almost everyone around us, but certainly known to those like us who feel the stigma of our stoma on a daily basis.

And now comes the exciting part! "What should I, could I, wear today to make me feel beautiful again on the outside while healing on the inside?" Welcome to "Ostomy is in Fashion!" and get ready to Wear It Out by Manny.

With the arrival of summertime, it's time to be colorful no matter our size or shape. Be courageous and try on some turquoise for the day or a shade of lavender. Soft pastels are very comforting and provide that splash of color to lighten things up. Remember—fashion is for everyone!

Warmer weather means it's time to continue to shed the heavy materials of winter. Put away your flannels and bulky cover-ups! Then break out the linen and cotton. These are two of the ideal summer fabrics. To stay cool in the warmer months, the idea is to allow for the maximum amount of air to pass through a fabric. Generally speaking, lightweight fabrics wear cooler than heavier ones. Spring and summer are times for lighter materials in both appearance and feel. The obvious practice is to reflect the warmer colors of life, while trying to keep the body as cool as possible. Fabric makes the biggest difference in body temperature regulation, limiting how much you sweat. The colors you choose are up to you, be bold-show the world some of your inner spirit by bringing it to the outside!

After professing my love of warm weather fabrics I am always asked where to acquire such items. Paul Stewart and Suitsupply do an excellent job of incorporating seasonal fabrics into their collections. Lands' End and Zara also have a few jackets, pants and shirts in linen. Given my own talent and expertise for custom and made-tomeasure garments, I would recommend places like Wear It Out by Manny, or any other tailor that carries seasonal fabrics.

So, don't forget, during the warmer months, linen and cotton fabrics are your best friends and keep the lining to a minimum. And, remember, we are all beautiful...inside and out. Ostomy IS in Fashion. *Wear It Out...and Wear It Well.*

What do you wear to feel beautiful?

Send us a photo of yourself "wearing it well" and you may be featured in an upcoming eNewsletter. Email us at securestartnewsletter@hollister.com.

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

Get Back in the Game

Exercise your fitness options with these helpful tips

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

It can be daunting to think about exercising or engaging in your favorite sports after ostomy surgery, but you can do it! We're here to coach you with these tips and advice.

When is it safe to start exercising after ostomy surgery?

Stoma surgery is a major event that should not be underestimated. The first few weeks or even months following the operation may be difficult as you adjust gradually to having a stoma. The easiest and most effective form of exercise can be walking. It's best to check with your healthcare provider to determine the right time for you to begin exercising, as every person can be different.

I'm nervous about doing sit-ups and crunches because I have heard that I could develop a hernia. Are there precautions I can take to avoid this?

There may be a risk you will develop a hernia around your stoma that can be associated with straining on heavy lifting and during strenuous abdominal activity. You can help prevent the development of a peristomal hernia by taking certain precautions. Keep your weight in check and talk with your surgeon before resuming any abdominal exercises.

I love aerobics but I worry that all of that motion might cause pouch leakage. What can I do to minimize this?

Similar to participating in other sporting activities, you can wear certain clothing that can help ease your concerns. Use a support garment or a girdle to keep the pouch securely in place. Try different sporting outfits, such as running tights or Lycra® shorts to see what works best for you.



Should I drink anything special to stay hydrated while

To help hydrate your body, water is the best fluid as it is the most readily available. You can also get special rehydrating solutions from most pharmacies.

How will I know that I am sufficiently hydrated?

One good sign of being well hydrated is passing clear or straw-colored urine throughout the day. Dehydration is a major concern for overachievers, whether they have stomas or not. Drink plenty of fluids at every opportunity to avoid problems with your stoma and with dehydration.

I am still very tired after my surgery. What kind of exercise can I do to start out?

Begin by walking in your house. Special videos and DVDs, or even just some invigorating music will help set the pace. You might practice going up and down stairs to increase stamina and endurance. But, if weather permits, walk outside in the fresh air to help boost your physical and mental spirits!

Is there a special diet I should follow once I get active again?

Once you recover from surgery, your diet and state of nutrition should be getting back to normal. How and what you eat is as much a part of our individuality and lifestyle as our appearance and personality. Having a stoma should not restrict your individual preferences. It is important, however, to remember that chewing food thoroughly helps to avoid some possible digestive problems.



ASK THE EXPERT

Get Back in the Game (continued)

I love swimming but I'm nervous that my pouch will become loose in the water. Is there anything I can do to make sure this doesn't happen?

This is a valid concern for a person with an ostomy. To determine how your pouch might perform while swimming, it is recommended to "test" your pouch. Sit in bath water for a while and assure yourself that the seal stays snug and leak-free.

My friends and I play rugby and I'd like to get back on the team, but I don't want to damage my pouch or stoma. What can I do to protect it?

Having a stoma will mean planning ahead, but you can continue to participate in contact sports. You should take precautions to protect your stoma. For added security, some people use support garments or girdles to keep the pouch securely in place.





I ran my first marathon after ostomy surgery and little red marks appeared on my stoma. What are these and should I be concerned?

With a lot of running, little red marks similar to mouth ulcers might appear on the stoma because of rubbing or chafing. They should heal quickly and disappear with rest. If they don't resolve, contact your healthcare professional.

When I exercise I perspire a lot. Is there anything I can use to avoid chafing around my pouch?

If your pouch fits properly and is not too long, it should not touch or rub against the skin. Empty your pouch before any strenuous activity as well to decrease the weight of your pouch. Consider using a pouch that has a comfort panel to avoid the pouch film from rubbing against your skin.

How can I get in touch with someone with an ostomy that rides horses? I want to get back in the saddle!

If you would like to talk to someone about a particular sport, such as horseback riding, contact the United Ostomy Associations of America (UOAA). They may be able to put you in touch with someone who currently enjoys the same sports you do and with someone who can give you some practical advice.

Have a question that wasn't answered here? Check out this helpful new brochure from Hollister Incorporated. Living with an Ostomy: Sports & Fitness Or call us today at **1.888.808.7456**.

EVENT UPDATES

United for Education, Advocacy and Fun

UOAA prepares for their sixth biennial National Conference

Clear your schedule and book your ticket because you won't want to miss the sixth biennial United Ostomy Associations of America (UOAA) National Conference in Irvine, California, August 22-26.

"People come from all over the country to see old friends and have fun," explains Ed Pfueller, Communications Manager at UOAA. "But the conference is very welcoming to first timers as well."





A First Timers Orientation is planned where people can pick up tips from others and make new friends. The conference also offers a wealth of educational sessions targeted to specific concerns, a stoma clinic, support group leadership academies and motivational speakers.

The festivities will begin with a presentation by Yachtswoman, Pam Wall, who raised a family aboard a 39-foot sloop while managing her ostomy without the benefit of a shower or flushing toilet.

Of course, fun is on everybody's to do list and there will be no shortage of that this summer. Participants can attend an ice cream social, join a fun run or enjoy a barbeque by the pool. And don't forget Disneyland is a hop, skip and a jump away.



Motivational Speaker Joanna Burgess-Stocks, BSN, RN, CWOCN will cap off the conference with her presentation, "Stepping Stones, Understanding the Power and Importance of Your Story." Joanna has lived with an ostomy since the age of three, serves on the Management Board of Directors of UOAA and is chair of its advocacy committee.

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All photos: Participants at the 2015 UOAA Conference enjoyed socialization, educational sessions, support groups and speakers!

"We want everybody's voice to be heard. This is an easy way to mobilize people for action." -Ed Pfueller



EVENT UPDATES

United for Education, Advocacy and Fun

Make your mark today with the UOAA

Apart from the upcoming conference, the UOAA is working tirelessly to advocate for the rights of people with chronic conditions on the national level. They advocate on Capitol Hill and also by using an online advocacy technology tool to alert members and the ostomy community to various issues and help them contact their elected officials.

And there's even more on the horizon! Don't miss the fourth annual Run for Resilience Ostomy 5K in Durham, North Carolina, on October 7. Other runs will be held in Cookeville, Tennessee, on October 7 and in Boise, Idaho, on October 14. Runs in Portland, Oregon, are still to be announced. You can even run or walk your own virtual 5K race on October 7. All proceeds benefit the UOAA. To sign up for a race and additional information go to **ostomy5k.org**.

Go to **ostomy.org** for more information or to register for the UOAA National Conference.

EVENT UPDATES

Other Ways to Get Involved

Summer and Fall 2017 Event Updates

Ostomy Awareness Day October 7 www.ostomy.org

Youth Rally July 17-22, San Diego, CA www.youthrally.org

Take Steps for Crohn's & Colitis **Register for a Walk for Cure**

Run for Resilience Ostomy 5K October 7, Durham, NC October 7, Cookeville, TN October 14, Boise, ID www.ostomy5k.org



2016 Youth Rally Campers



WHAT'S SO FUNNY?

Pedaling Through Life with an Ostomy

Brenda takes on hills and spills with laughter



Who would have thought that an ostomy would be the key to changing a life-long struggle with weight? I was sitting at the United Ostomy Associations of America (UOAA) National Conference in 2005, when a guy who looked to be about 50 years old got up in a biker's shirt to relay his experience riding in an event called Get Your Guts in Gear (GYGIG). It was a 210-mile, three-day bike ride. He had an ileostomy and they even slept in tents! My first thought was, "That is nuts!" But, as he talked, I was overly interested and the dialogue began in my head. "I used to like biking; it's probably been 10 years since I exercised. I wonder if I could ever do that." Years earlier, I tried to bike, but since my surgery for colon cancer and extensive female surgery, it was uncomfortable so I gave up.

Later, I sought out the ride director and asked, "Could a person like me, with two bad knees, who hasn't exercised for a decade actually do this ride?" I was a 49-year-old, 350-pound woman who had been overweight since high school. Without hesitation he answered, "With your doctor's permission and proper training, I don't know why you couldn't." I gulped. I went home to try to put it out of my mind but, like a painful hangnail, it wouldn't leave.

I asked the knee doctor, "Will I wreck my knees more if I do a bike ride like that?" "You couldn't hurt them worse than they are already. I'll give you cortisone shots to get through it." Dang. A client told me about a three-wheeled recumbent bike with a big padded seat. I went to inquire about it from the bike shop owner. "Could a person like me ride a bike like that in a 210-mile, three-day bike ride in the state of Washington?"

(continued on the next page)

WHAT'S SO FUNNY?

Pedaling Through Life with an Ostomy

(continued)

"No way," he answered quickly. I let out a sigh of relief. Then he added, "That would take too long, but I think you could do it with a two-wheeled one." Panic set in but I told him what the ride was for and how I had to raise \$3,000. Then I had an idea, "How would you feel about lending me a bike for the ride and training me? In exchange, I'll advertise your store and have your bike displayed at my upcoming comedy show." This was a lot to ask of a complete stranger and I was pretty confident he'd say no, but he said, "Yes, I think I can do that."

It was April Fools' Day 2007 and I thought he must have been joking. He taught me about balance in the strip mall parking lot, and in two weeks I set off to go a mile. The first block was easy but as I tried climbing a very small hill, over I went. I felt humiliated and my legs were throbbing from the falls. It took a lot of self-talk to try again. "Come on Brenda, lift your foot off the ground, you can do this, you'll be okay." I was paralyzed with fear. After 20 minutes, a little boy yelled from his front door, "Hey lady, watcha' doin'?" "I'm riding my bike," I yelled back. "No you're not," he answered. And then I laughed because he was right. When I finally quit taking myself so seriously, I was able to lift my foot off the ground, rode my bike the two blocks home and parked it there a couple of days before I got my nerve up to try again.

This was the beginning of a transformation. One of my friends who biked with me the first time I rode 14 miles started calling me an athlete. I remember praying to all my obese relatives in heaven to help me return from those 14 miles—and I made it. By July I was biking 100 miles a week and feeling fairly prepared. When I went to Seattle, everyone zoomed by me on the first hill and I rarely saw them again unless they were lagging behind and we were going downhill. Then gravity took over, and I sailed past them...for a moment. I rode my bike for eight hours a day and still couldn't catch up. Reluctantly, I had to take the sweep van several times up the biggest hills to stay on track and arrive to camp before dark. I made it 150 miles over those three days and I had time to reflect. What seems obvious to most people was new to me and I had a realization, "Perhaps I need to lose weight; these skinny people are passing me up."

"I am grateful for my fellow ostomates who inspired me..."

Over time, I quit eating sugar, white flour and drinking alcohol. And, with the help of some good friends, I still focus on it one day at a time. I lost 150 pounds over the next two years and when I went on the next bike ride for GYGIG, it was a two-day, 150-mile ride and I did every mile.

It's a challenge at times but, I'm always grateful for my life-saving ostomy. Today I am 10 years older and still do bike rides, walk 5Ks, play racquetball and swim—things I wondered if I'd ever do again. Life is good and physically easier these days and I am grateful for my fellow ostomates who inspired me and showed me that anything is possible. By the way, I bought the bike. He gave it to me for a huge discount. After all, "It was used," he said.



Brenda 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.

A Friend "Just Like Me"

Shadow Buddies comfort our littlest members



Going through ostomy surgery is hard enough for an adult, but imagine going through it as a child. Shadow Buddies comes to the rescue with a soft muslin doll designed with a stoma and a detachable pouch. The huggable dolls have heart-shaped eyes for love and a smile that never fails, no matter the situation. A mom, whose son needed a stoma, designed the dolls to help educate caregivers and children alike. For each child, the Ostomy Buddy becomes a friend "just like me." Hollister Incorporated is proud to be the exclusive partner of the Ostomy Buddy.

To learn more about Shadow Buddies please visit **shadowbuddies.org**.

Ostomy Shadow Buddies are available through Hollister Incorporated in partnership with the Shadow Buddies Foundation.

Call us today for more information at **1.888.808.7456**.

Thanks for your feedback!

Last issue we shared a link to a 75-second survey created to help Hollister Secure Start services better understand your needs in living with an ostomy and where you could benefit from more support. Your input will help us continue to evolve our services and we look forward to sharing those with you in the months ahead.

We always love hearing from you so call us at **1.888.808.7456** and let us know how we can help!



"Thank you for sharing your time with us and allowing us to better serve you." -Hollister Secure Start Services

Q2 **2017**

Share Your Story

We'd love to hear about your journey!

Though we all share the ostomy experience in one way or another, each one of us is unique. We'd love to hear your story. There just might be someone out there who needs to hear it too.

Have you...

- Done something daring?
- Found new inspiration?
- Made a difference in the ostomy community?



Please share your journey 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.

"When you stand and share your story in an empowering way, your story will heal you and your story will heal somebody else."

—Iyanla Vanzant



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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

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



Hollister Incorporated 2000 Hollister Drive Libertyville, Illinois 60048 USA

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