Secure Start Newsletter Q4 2015

Cover Story
Rock Your Bikini

Highlights:
- Ask the Expert
- Secure Start Corner
- WannaWearOne 5K Race Results
- Secure Start Year in Review
When I woke up in the ICU after ileostomy surgery at twenty-one years old, my first words were, “Who’s going to love me and how am I ever going to wear a bikini?”

I’m here to tell you that I now have a boyfriend who loves me to the bone, and ironically I just competed in a bikini-modeling competition in front of hundreds of people. Let me explain. Bikini Fitness competitors model on the catwalk and are judged by physique and muscle tone. I trained for fourteen weeks, which consisted of rock climbing twice a week, wakeboarding three days a week, and working out in the gym two hours every morning—Monday through Friday.

Believe me, the journey wasn’t easy. That day in the ICU my mom turned to miserable little me and said, “Buck up and put on your big girl panties. If you can get through this, you’re going to be able to help someone else some day.” Little did I know that she would prove to be right.

But back then I hated every minute of it—my skin was so broken down that I had a hard time keeping my pouch on. My brothers remember me kicking and screaming with every pouch change because it hurt so much. I call my surgeon my “savior”, but Pam Achabal—my Secure Start coordinator—really “saved my life” when it came to living with an ostomy. She was helpful with the issues I was having with skin breakdown and worked with me until I was comfortable with my pouching system. Her wealth of knowledge helped me through it all and inspired me to challenge myself.

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I became a massage therapist and was working in a chiropractor’s office when I had the opportunity to work with a young adult patient. As I was looking through his paperwork, I realized the reason for his visit was a concern regarding his ulcerative colitis. Tears started pouring from my eyes. I said to myself, “This is it—your chance to help someone.” I made the connection with him and his mom and said, “Look, I’ve been through it and you’re not alone.” We’ve been the best of friends ever since. I have realized that my purpose in life now is to mentor others. If I can relate to someone and help them cope, I have achieved my purpose. In fact, Hollister has invited me to speak to doctors and nurses about my experiences, and I love it. Because—let’s face it—hearing a journey from a patient’s perspective speaks volumes.

You’re probably wondering how I got into Bikini Fitness. Before surgery I was super active and played competitive sports in high school. I had been working with a trainer for the past couple of years and felt like I had reached a plateau. There was a missing piece to my puzzle. Then I walked into a nutrition shop and saw bikini models rocking the cover of a magazine and thought to myself, “This can’t be a reality for someone like me, but how did these girls achieve their goals and create a physique like this?” My nutritional coach gave me some information about the program they followed and introduced me to a professional bikini competitor. It was at that very moment that I accepted the challenge to compete. My coach now has me on supplements and a meal plan that involves eating every two to three hours and that kicked me into gear. And, of course, I keep up my rigorous training schedule.

“If you can get through this, you’re going to be able to help someone else some day.”

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I have great support from family, friends, and my lovely clients in my hair salon and boutique that I consider “my family of choice”—and especially my boyfriend. He met me after my ostomy surgery and even witnessed a flare-up, which gave him even more respect for everything that I have been through. This support means a lot to me, especially when I remember that one of my biggest worries was finding someone who would love and accept me for who I am.

As I go through my day, everybody wants to know how my training is going, and I know I’m not alone up there strutting my stuff on that catwalk. And remember—you are not alone, either.

Financial Disclosure: Amber Daniell received compensation from Hollister for her contribution to this newsletter.

Amber's most recent bikini-modeling competition
In many parts of the country, winter brings a flurry of snowflakes. Each snowflake is unique and has its own shape and size. Children love to catch them on their tongues, while we adults often grumble about shoveling once they pile up. Like the seasons, often our needs change when it comes to wearing a pouching system.

Like snowflakes, there are many different types of ostomy pouches, and each has its own unique characteristics. All ostomy pouches will collect the stoma output and should be odor proof. The type of pouch you choose will depend on the type of stoma you have and its output, as well as some personal preferences. In the hospital, product choices are somewhat limited. During this early period, the requirements of the pouching system are different. After you get home you will begin to assume more responsibility for your own care. At this time, you may want to consider product options that were not available in the hospital.

There are two types of pouching systems: a one-piece and a two-piece pouching system. Your Wound Ostomy Continence (WOC) nurse may recommend the type of pouching system that is best for you, but you can play an active role in this decision by having the right information. You can also ask the Secure Start service team members to answer any product-related questions you may have.

One-Piece Pouching Systems: For this type of system, the skin barrier and the pouch are a single unit. For some, the one-piece pouching system is easy to apply – just peel and stick. This type of pouch may lie more flush against your skin and may not be as noticeable under clothing.

Two-Piece Pouching Systems: For this type of system, the skin barrier and the pouch are two separate pieces. The plastic ring in a two-piece system, called the flange, is used to connect the two parts together. This system will allow you to see your stoma when applying the barrier before the pouch is snapped on. The two-piece system will also allow you to apply a new pouch without removing the skin barrier from your body each time. You can wear a different pouch depending on your activity. For example, you can change to a smaller pouch when you are swimming or intimate, and then switch back to a larger pouch afterward without having to change the skin barrier.

Whether you use a one-piece or a two-piece system, you need to be sure you are using the correct pouch. If you have a fecal stoma you can choose a drainable pouch or a closed pouch. If you have a urinary stoma you will use a urostomy pouch.
A Pouch for All Seasons
(continued)

Q: Should I use a drainable pouch?
A: A person with an ileostomy or colostomy should use a drainable pouch because they will need to open the pouch and allow the stool to empty numerous times per day. The end of the pouch is closed with either a pouch clamp or a closure that is integrated into the pouch.

Q: Should I use a closed pouch?
A: A person with a colostomy may choose a closed pouch. Closed pouches do not have pouch clamps or integrated closures. Basically, you remove the pouch and throw it away when it is 1/3 to 1/2 full. It is a good option for people who would normally empty their pouch once or twice per day. A person with an ileostomy may also choose a closed pouch for short periods of time when they would prefer something more discreet, such as when swimming, cycling or being intimate.

Q: Should I use a urostomy pouch?
A: A person with a urostomy would choose a urostomy pouch. This pouch has a tap at the bottom of the pouch that allows the urine to be drained frequently throughout the day. At night, a flexible tube and drainage collector can be connected to the tap of the urostomy pouch with an adaptor. This tube allows the urine to flow into the drainage collector while you are sleeping. This option may be preferable to getting up during the night to empty your pouch.

It is important that you use the correct pouch, but not all pouches are the same. There are characteristics and features that will help personalize the pouch for you and your lifestyle. You may want to consider some of these options when choosing the right pouch for you!

Pouch length: There are a variety of pouch length options to best meet the needs of different body sizes. However, you do not want to choose a pouch that is too small as you will need to empty it more frequently.

Pouch film: Pouches are available in different transparencies. A transparent pouch allows you to see the contents of the pouch, whereas a beige pouch helps to conceal the contents and usually does not cost more than the transparent option.

There are also pouches with a “viewing option” which allows you to have a beige pouch with a “window” for you to see the stoma and pouch contents.

Filter: A filter helps eliminate pouch ballooning by continuously venting and deodorizing the gas that goes into your pouch. This feature may also help the pouch remain more discreet by having a lower profile.

Ultimately, the pouch you choose should be based on the type of stoma and its output. The features of the pouch should meet your personalized needs. It is important to remember that the pouching system should fit well and there should be no leakage issues between pouch changes. Your skin should also remain healthy and intact. If you have any problems, please contact your WOC nurse, or your Secure Start coordinator at 1.888.808.7456.
Secure Start Corner

Meet the smile behind the voice

Francois
Region: East
Title: Lifetime Service Coordinator, Ostomy Care
Length of Service: 4 years
Hobbies: Working out and hanging out with my son
Favorite TV Show: Empire
Interesting Tidbit: The Denver Broncos and the Cleveland Cavaliers are my favorite sports teams.

Andrea
Region: Midwest
Title: Home Health Coordinator, Ostomy Care
Length of Service: 24 years
Hobbies: I enjoy walking, biking, scrapbooking, shopping and gardening.
Favorite TV Shows: Flea Market Flip and House Hunters
Interesting Tidbit: I enjoy spending time with my grandson.

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NEWS FROM HOLLISTER

Secure Start Corner

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Jairo
Region: Southeast
Title: Acute Care Coordinator, Ostomy Care
Length of Service: 1 ½ years
Hobbies: Working out and exploring Chicago
Favorite TV Shows: *Shameless*, *The Wire*, and *Boardwalk Empire*
Interesting Tidbit: I am fluent in Spanish.

Emily
Title: Lifetime Service Coordinator, Continence Care
Length of Service: 1 year
Hobbies: Running, biking, spending time with friends and family
Favorite TV Show: *Grey’s Anatomy*
Interesting Tidbit: I studied abroad in Barcelona, Spain.
On October 3, 2015, two Wound Ostomy Continence (WOC) nurses from the Triangle of North Carolina took World Ostomy Awareness Day to heart and hosted the second annual WannaWearOne (WWO) Ostomy AWEARness 5K Race. The race helps raise awareness in that wearing an ostomy pouch does not prevent you from doing day-to-day activities including running a 5K. In fact, non-ostomy participants were given an ostomy pouch in their swag bags and encouraged to wear it during the race.

For the second year in a row, the race was held on the American Tobacco Trail in Durham, North Carolina. Despite bad weather due to Hurricane Joaquin, 110 people participated in this family-friendly race. Fun included a face painter and a balloon artist.

To cast a wider net, United Ostomy Associations of America (UOAA) developed the Virtual Run. This option allowed anyone to sign up for free or optionally pay $15 for a race shirt and run a 5K anywhere while spreading ostomy awareness. Sixty people from 23 different states and three countries (Japan, South Africa and Canada) participated in the Virtual Run. In fact, the UOAA encouraged people to take photos of themselves doing the virtual race to post on the race website.

Hollister joined in the festivities with platinum sponsorship of the races. Nearly 20 Secure Start associates participated in the WWO events in North Carolina, Oregon and a virtual walk in Wheaton, Illinois. They were also able to join the Ostomy Support Group Mesa-East Valley, Arizona in their World Ostomy Day Picnic. Race participants received IBD & Ostomy Awareness Ribbons. The stylish brown ribbons with signature red crystal, representing an ostomy, destigmatize IBD and ostomy surgery.

Overall, the WannaWearOne Ostomy AWEARness 5Ks raised over $40,000 for the UOAA, a non-profit 501(c)(3) organization whose mission is to establish community ostomy support groups nationwide, and promote community, ostomy education, empathy and awareness. Mark your calendars for the next World Ostomy Day (October 1, 2016), where the 3rd annual events will be held in North Carolina, Oregon and hopefully a location near you!

To find an upcoming race or to get involved, go to Ostomy5k.org for details.
Hello! I want to begin by thanking everyone for making 2015 a remarkable and memorable year!

Throughout the year, we had several opportunities to personally connect with our customers. It started with the launch of our new "Welcome to the Family" Facebook page and continued to our booth at the United Ostomy Associations of America (UOAA) National Conference in St. Louis. It has been a pleasure getting to know some of you online, while also meeting a number of you in person. We were able to learn more about you, and we hope that you learned a little bit about the Secure Start family as well.

And then there were your truly remarkable stories. We were proud to feature people who possessed the courage to share their personal, often difficult, journeys of living with an ostomy. Our newsletter kicked off 2015 with Alaina Fisher, a college student who refused to let an ostomy break her spirit, or her school spirit. Then, we traveled back to the 70s when Mike Adams reflected on his ostomy journey which began in 1972. In Quarter 3, Brenda Elsagher inspired and encouraged us to find humor even in the darkest of times – congratulations to her on living with laughter for 20 years! And, in this issue, Amber Daniell relates how she uses her life-changing surgery to motivate and help others.

It was also a year of challenge. The anti-smoking campaign, initiated by the Centers for Disease Control (CDC), was a wake-up call for the entire ostomy community, including us. There is more work to be done in educating others that living with an ostomy is not something to be stigmatized by or be embarrassed about. We used World Ostomy Day in October to raise awareness that living with an ostomy can be both liberating and life-saving. In solidarity with UOAA, Lara Leininger, Angela Richardson, Lois Fink, Bret Cromer, Lauren Fortino and Cheryl Ory that day proved that we are all in this together.

As the year comes to a close, I again thank you for enriching our lives with your unwavering courage and inspiration. We look forward to sharing more memories together in 2016!

Have a safe and happy holiday season!
Secure Start services

We Want You To Join Us

You talked. We listened. And we’re not stopping there.

What matters most to you, matters more to us. By listening to you, we can be sure the new services we offer today and in the future are focused on your biggest concerns and needs as a person living with an ostomy.

So, what have we heard? You indicated a need for more information on managing skin-barrier leakage and skin irritation. This topic will be the focus of our first session in our NEW educational webinar series launching soon.

Secure Start services provides personalized support at no cost to you, so you can live your life, your way. Enroll today to learn more about the new services created with you in mind and how Secure Start services can help you today, tomorrow, and for a lifetime. www.securestartservices.com

Secure Start services has a new Facebook page!

This is a great place to meet people, whether you are living with an ostomy or caring for someone with an ostomy. Our Facebook page is the place where we share our celebrations and events, photos, videos, and even recipes. We invite you to share your stories, too! Join the conversation today by clicking the link above. Welcome to the Family!
Share Your Story

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

Secure Start Newsletter Resources

**Secure Start services**
1.888.808.7456
www.hollister.com

**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

**Youth Rally**
www.youthrally.org
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