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A Quarterly Newsletter for People with Ostomies

Teens Rap to a New Beat

Young people with ostomies find new ways to keep up with their old tricks

What's up with teens and tweens with ostomies? The same stuff that concerns everybody else. "Will I fit in?" "What if someone finds out I'm different?" "Is my favorite pair of jeans clean?" "Will I get a goal in soccer?" Though zits and bad hair days seem tame compared to an ostomy, things don't have to change drastically after surgery.

"People with ostomies have done everything, like surfing and becoming Rhodes Scholars," said Beth Harrison, Pediatric WOCN at Children's Hospital Los Angeles. "Once they've mastered this, nothing in life will ever seem hard."

Hospitals from coast to coast employ nurses like Beth who make it their job to help young people hip-hop their way right back into their day-to-day lives. For example, before surgery, Beth takes a look at a teen's wardrobe to determine his or her style (hip-hop, rocker, punk or preppy) and suggests easy ways to adapt it to accommodate the ostomy. She also helps determine the most convenient spot for the stoma and suggests pouching options.

In most cases teens and tweens can get back onto the field or into the pool after a recovery period. A simple hernia belt with a prolapse flap can provide comfort and protection during soccer or football games. The **New Image 7"** Closed Mini-Pouch from Hollister is great under leotards or gymnastics gear, and wetsuit bottoms offer extra support for swimming or surfing.

"No matter what activity people with ostomies choose, they need to make sure to get enough fluids and balance their diet," added Beth. "And, of course, find a pouching system that fits well and allows good wear time."

Most importantly, remember that you're not alone. There are tons of teens and tweens going through the same stuff you are. Look for a really cool teen/tween page and chat room on www.hollister.com by the end of the year. Want friends now? Check out YODAA (Young Ostomate and Diversion Alliance of America) at www.yodaa.org and Camp Oasis, sponsored by CCFA (Crohn's and Colitis Foundation of America) at www.cdfa.org. See you there!



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Wound, Ostomy and Continence Nurses Society (WOCN)

1.888.224.9626 www.wocn.org

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

1.800.932.2423 www.ccfa.org

Personal Profile**Forever Young*****Shaz runs an upbeat website from down under***

When Sharon Sandells, aka Shaz, had her ileostomy at age 10 due to ulcerative colitis, she kept a diary. Her first entry, dated January 7, reads, “Harriet, my stoma, was born.” Thirty-one years later, Shaz and Harriet use honesty and humor to inform, inspire and connect people with ostomies of all ages—especially teens and young adults.

Shaz’s Ostomy Pages is an interactive website created as an antidote to the typical “medical speak” sites. Viewers are immediately greeted by Bessie the Bag and her quote of the day. Then Shaz, whose devilish grin makes her appear perpetually young, ushers them in with her personal story, told in colorful, no-holds-barred language.

“I’ve tried to keep the site upbeat while still telling it like it is,” explained Shaz, who works as a data processor for the Diabetes Association. “People soon realize that it’s not only ‘older’ people who have ostomy surgery and that others their age have been there, done that and have the bag to prove it.”

The 10-year-old site is a cornucopia of information distilled into simple language, from how to irrigate your colostomy to pregnancy after an ostomy. But according to Shaz, the most valuable features are the message board and 24/7 chat room, where people make friends from around the world. There’s even a section on the message board expressly for teens.

“My favorite parts are the humor pages,” chuckled Shaz. “Check out the Ostomy Barbie®. I just think that a sense of humor goes a long way when you’re dealing with something like this. You can either be miserable and have a ‘woe is me’ attitude or you can laugh about it all and get on with living.”

Shaz lives life to the hilt in Perth, Australia, with Harriet and their cats, Leia and Xena. Visit them at www.ostomates.org.



Ask Brenda

Hats Off to John

A 17-year-old proudly wears his opinion of people with ostomies

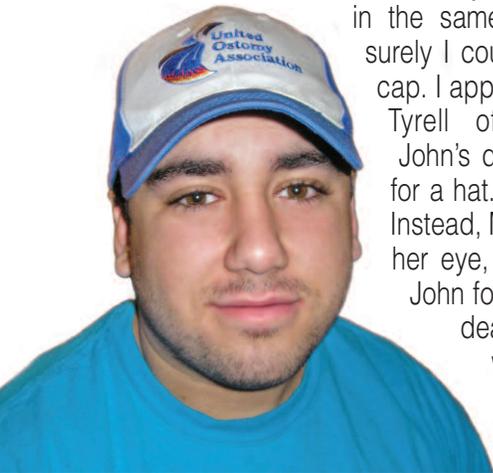
By Brenda Elsagher

While preparing to write this column, I asked my 17-year-old son, “Would you ever date a girl that had an ostomy?” Without a moment’s hesitation he answered, “Sure, why not?” I realize that he is an “informed” teenager when it comes to the world of ostomy. He has not only grown up with a mom who lives with an ostomy, but has been dragged along to many talks and fundraisers over the years pertaining to living with an ostomy.

Suddenly a memory flooded back to me from the last United Ostomy Association conference held in Anaheim, California, in 2005. John noticed that the board members sitting up at the head table wore commemorative hats that said United Ostomy Association on the front and the years the organization had existed on the back.

“Hey, Mom, any way you can get me one of those hats?” he whispered. I fired off, “You want one of those hats? The Ostomy Association hats? Why? Would you wear it to high school?” “Of course,” he answered matter-of-factly. Frankly, I wondered if he really would wear it.

I felt shy about asking a board member if I could buy a hat from them, but we mothers often step out of our comfort zones to satisfy our kids’ desires. Though deathly afraid, I have not hesitated to slay spiders or mice that were in the same room as my children; surely I could ask about a baseball cap. I approached Dan and Marilyn Tyrell of Michigan, explained John’s desire and offered to pay for a hat. They wouldn’t hear of it. Instead, Marilyn said with a wink in her eye, “I might give it away to John for the price of a hug.” The deal was sealed and John wore the hat proudly during the rest of our stay in California.



Brenda’s son John proudly wears his United Ostomy Association hat



When school started, John plopped on his hat as he walked out the door. After he came home I confronted him, “Did anyone ask what the United Ostomy Association was?” “Sure, all the time—teachers and students,” he replied. Curious, I asked, “What did you tell them about it?” “I told them it was an association of people that had ostomy in common,” he explained. “Then when they asked me what an ostomy is, I told them it’s when people have to wear a bag or a pouch because their colon and stuff has been rerouted.” I prodded him for more: “Do they ask more questions after that?” “Nope,” he said with a smile. “They usually just walked away kind of fast.”

“Our ostomies are a small part of us that others have to get used to.”

He must have put more thought into dating someone with an ostomy as he did his homework, because he came to me later and said, “Mom, it wouldn’t bother me because I know what it is because my Mom has one. If you’d never heard of it, though, you might have to get used to it,” he added.

Since I was married when I found out I had colon cancer and consequently had my ostomy, I never experienced the stress of dating while living with an ostomy. Dating without one was traumatic enough.

I always learn so much from my kids. John’s words held a lot of simple wisdom. If someone cares for you, that person will get used to your ostomy. We are all much more than our ostomies. We are whole people with great love, humor and passion. Our ostomies are a small part of us that others have to get used to. And this can happen only after we start getting used to ourselves.

Brenda Elsagher is a funny national keynote speaker, author and person living with an ostomy for 11 years. Her books, *If the Battle Is Over, Why am I Still in Uniform?* and *I’d Like to Buy a Bowel Please!* are available at www.livingandlaughing.com. She also welcomes questions or comments about this column. Please contact her at Brenda@livingandlaughing.com.

Talking Points

Big Coverage for Small Products

Deanna Eaves tracks reimbursement for mini-pouches, stoma caps and Adapt Lubricating Deodorant

When ostomy products are provided to a customer, the supplier of that product usually sends an insurance claim to the customer's insurance company. Instead of writing the actual description of the product (for example, "drainable ostomy pouch with a filter and flat standard-wear barrier and an integrated closure") on the insurance form, each product is assigned a billing code based on the Healthcare Common Procedure Coding System (HCPCS). These codes break down the common characteristics of ostomy products (and other medical products) into categories and make it easier for the insurance administrator to understand what product was provided.

Additionally, these HCPCS codes are usually assigned a dollar amount that the insurance company will approve for that type of product (a fee schedule). Because each insurance company is different and many base their practices on what Medicare does, this article will focus on the Medicare fee schedules and guidelines for usage.

A group of clinicians and insurance professionals known as the HCPCS Coding Panel assigns the more than 10,000 HCPCS codes. Since there are already several codes to manage, the panel strives to make the categories as broad as possible. The table to the right provides the HCPCS (billing) code for Hollister

HCPCS Code	Description	Medicare Max Utilization	Medicare Fee Schedule
Drainable Mini-Pouches—Two Piece			
A4425	Ostomy pouch, drainable, for use on barrier with nonlocking flange, with filter (2-piece system), each	20 ea / mo	\$3.58
A5063	Ostomy pouch, drainable, for use on barrier with flange (2-piece system), each	20 ea / mo	\$2.70
Drainable Mini-Pouches—One Piece			
A4388	Ostomy pouch, drainable, with extended-wear barrier attached (1 piece), each	None Published	\$4.36
A4390	Ostomy pouch, drainable, with extended-wear barrier attached, with built-in convexity (1 piece), each	None Published	\$9.61
A4424	Ostomy pouch, drainable, with barrier attached, with filter (1 piece), each	20 ea / mo	\$4.75
A5061	Ostomy pouch, drainable, with barrier attached (1 piece), each	20 ea / mo	\$3.52
Closed Mini-Pouches—Two Piece			
A5054	Ostomy pouch, closed, for use on barrier with flange (2 piece), each	60 ea / mo	\$1.79
A4419	Ostomy pouch, closed, for use on barrier with nonlocking flange, with filter (2 piece), each	60 ea / mo	\$1.74
Closed Mini-Pouches—One Piece			
A4416	Ostomy pouch, closed, with barrier attached, with filter (1 piece), each	60 ea / mo	\$2.75
Stoma Caps			
A5055	Stoma cap	31 ea / mo	\$1.44
Adapt Lubricating Deodorant			
A4394	Ostomy deodorant with or without lubricant, for use in ostomy pouch, liquid, per fluid ounce	None Published	\$2.58

mini-pouches, stoma caps and **Adapt** Lubricating Deodorant, as well as their descriptions, Medicare fee schedule amounts and usage guidelines. The fee schedule amounts are for each pouch, each stoma cap or each ounce of Adapt Lubricating Deodorant.

Please note that mini-pouches do not have special HCPCS codes. The size of the pouch was not a feature that was broken out by the HCPCS Coding Panel. Therefore, the same billing codes used for full-size pouches with the same features will be used for mini-pouches. The same can be

said for the pouch closure on a drainable pouch. There is no additional money given for an integrated closure than for one that requires a clamp. In addition, since Adapt Lubricating Deodorant is paid for by the ounce, it does not matter whether you get the 8-ounce bottle or the convenient box of 50 take-along packets.

As stated earlier, these are the Medicare guidelines. Each insurance company is different and therefore you should check with your insurance company to see how it will pay for each of the products that you require.



Frequently Asked Questions

Straight Talk for Teens

Life in the fast lane goes on with a few easy adjustments

Having an ostomy at any age is an adjustment, but when you are a teen it may seem overwhelming. Remember that you are not alone. There are many teens who have ostomy surgery every year. Here are some questions and suggestions that may help.

How do I tell people about my ostomy?

How you handle it is an individual decision. When you decide to share, it's helpful to know who and when you want to tell. Keep the explanation simple. It may help to rehearse with a parent or a sibling. Most teens find that close friends don't treat them any differently and, in fact, are curious to know more. It also relieves a lot of stress to share this with a good friend.

How do I control the odor?

As long as your pouch is secure, there should not be an odor. When you empty your pouch, you may find it helpful to flush the toilet at the same time as emptying and to use an odor eliminator in the pouch. This needs to be reinserted when you change or empty the pouch. Always wipe the bottom of the pouch off to avoid odor.

How do I prevent leakage?

Nothing is 100 percent guaranteed, but planning ahead can make a big difference! Get familiar with the wear time for your pouching system. Change your pouch on schedule and don't push your time limit. Think through what could happen and plan for it. Keep extra ostomy supplies in an inconspicuous bag and an extra change of clothes in your locker or backpack.

Can I wear regular clothes?

Most teens find that they can wear the same clothes that other kids their age are wearing. Talk with your WOC nurse and experiment with different pouching options such as one-piece, two-piece, beige and different sizes. Some may work better under your specific clothes than others.

Can I participate in sports?

Depending on how recent your surgery was and your overall health, you can probably participate in the same individual and team sports as you did prior to your surgery. It is best to check with your surgeon to see if you are ready for any activity. Protect your stoma from direct blows. Remember that you cannot feel the stoma. Also drink enough fluids so you don't become dehydrated. Many teens also find that they need to change their pouch more frequently when they sweat.



Someone You Should Know at Hollister

Ellen Sofie

Consumer Programs Manager



Need a sample of a new product? Got a question about how to use it? Care to share suggestions for improvement? Ellen Sofie's team is at the other end of the line to listen, suggest and speed samples directly to your door.

"Please feel free to call or e-mail," urges Ellen. "We really care about you and want to be there for you."

Ellen shepherds a flock of 10 consumer representatives. Six representatives field calls and e-mails from clinicians and customers. The other four do follow-up and troubleshooting after samples are sent. Hollister considers them the voice of the customer, and monthly meetings with the marketing and clinician groups provide a forum for product instruction, feedback and suggestions.

"The only way we can improve our products is to listen to our customers and treat them with compassion," said Ellen.

Ellen brings 20 years of customer service management experience to Hollister. In past positions with Xerox, Zeller Plastiks and Cardinal Health, Inc., she dealt with distributors and hospitals, so her job as Manager of Consumer Programs came as a refreshing change. She loves relating directly with customers, especially since she also had an ostomy, which doctors were able to reverse.

"For me things have come full circle," she said. "I used Hollister products and now I can make a difference in the lives of others who use them. It's like getting paid for volunteer work—and I love it."

To speak with a member of the Consumer Programs Team please call 1.800.323.4060, select Option 3, Monday through Friday, 8:30 a.m. to 5:30 p.m. CST.



Announcements/What's New

Get Your Guts in Gear This Summer

Start training today! The Ride for Crohn's & Colitis is a three-day, 210-mile cycling event on two coasts that raises funds and awareness for Crohn's disease and ulcerative colitis. The New York ride is June 8-10 and the Seattle-area ride is August 3-5. All routes can be completed by a beginning rider with sufficient training and are challenging enough for a seasoned cyclist. Not into cycling? Become a volunteer! For more information go to www.ibdride.org.

Chapter Profile

What a Difference an "A" Makes

The First UOAA Conference ready to launch August 15-18

First kiss. First car. First job. Some firsts are unforgettable, and the first UOAA Conference planned for August 15-18 in the Chicago area promises to be one of them. The conference theme, "What a Difference an 'A' Makes," says it all.

"We're showing the difference between the UOA and the UOAA by pulling out the letter 'A' in various words, like 'attitude,'" explained Kristin Knipp, national conference chairperson. "We're a dynamic group of people who want to prove that our new organization will be around for a long time."

The conference promises to offer a dynamic series of firsts. The first-ever UOAA Golf Outing will take place on the Marriott Lincolnshire Resort PGA Championship course. Conference goers can crawl through "Coco" the Colossal Colon®, a 40-foot-long, 4-foot-tall model of the human colon. And closing speaker Craig Wilson will preview his documentary *Farang Ba* (Crazy White Foreigner), about his foray into boxing after his ostomy surgery in Thailand.

Exciting educational workshops are planned, on topics ranging from maximizing private insurance and Medicare to dealing with pelvic floor dysfunction. Major suppliers and manufacturers (including Hollister Incorporated) will showcase the latest ostomy products in one of the largest exhibitions to date. Special programming for teens and young adults will include a YODAA workshop on sex and relationships, a night out at a Chicago hot spot and a Teen Network session about dealing with depression.

"I am most excited to meet all of the new people," said Kristin. "They walk in having never met another person with an ostomy and leave feeling like they're part of a big happy family."

The UOAA Conference is one first you can't afford to miss, whether you're a 20-year veteran or someone who just had ostomy surgery. Look for registration forms in the June issue of the *Phoenix* magazine, go to www.uoaa.org or call 1.800.826.0826. Hope you join us!



UOAA
National Conference

August 15-18, 2007
Lincolnshire Marriott
Chicago Area

You're invited to the inaugural United Ostomy Associations of America's national conference this year! Don't miss the only national conference for ostomates and those with bowel and/or bladder diversions. Only minutes from downtown Chicago, highlights include:

- Golf Outing
- Over 40 Educational Workshops
- Cookout and Entertainment at Hollister
- Exhibit Hall
- Recognition Luncheon
- Closing Banquet featuring dinner, comedy and dancing
- And Much More!

For Additional Information,
call 800-826-0826
or visit www.uoaa.org



Report from Overseas

Hollister in France

The language of love is spoken loud and clear in the Paris office



When twin baby girls underwent ostomy surgery two years ago, three of the manufacturers of ostomy products in France had nothing that would fit them. Their mother contacted the Paris office of Hollister International and a sales representative made a beeline to the hospital with an idea and a prayer. **Adapt** Convex Rings and **Moderma Flex** One-Piece Pouching Systems (the European equivalent of **Premier** Pouching Systems) were lifesavers for the petite patients, and to this day their mother speaks to ET nurses about the tender loving care they received from Hollister.

“Hollister always focuses on the customer first, rather than just selling the product,” said Clementine Bouthors, Marketing Manager. “We get the product to them wherever they are.”

The French crew works its magic from an office in the heart of Paris near the Arc de Triomphe. Four people report directly to Clementine and provide marketing and product support for the 17 sales representatives who travel the country. Though Hollister has been in France for 15 years, the launch of new products such as **Pouchkins** Pediatric Pouching Systems and the extension of the **Conform 2** product line (the European equivalent of **New Image** Two-Piece Pouching Systems) have recently put the company in the limelight.

Clementine’s team trains the sales representatives, who in turn conduct informative workshops with ET nurses in public and private hospitals. French state health coverage (CMU) provides 100 percent reimbursement for ostomy supplies, and Clementine makes sure that Hollister products stay in the forefront of everyone’s minds. Each ostomy patient is given a kit that includes samples, a mail-in coupon for two free gifts and a membership application form for ILCO, the French association for people with ileostomies, colostomies and urostomies.

ILCO has 60 branches throughout France, and Hollister sends a sales representative to each meeting, along with refreshments

and extra financial support. Every two years, hundreds of people with ostomies meet at a national congress to socialize, swap ideas and learn about new products. At last year’s gathering Clementine presented the Hollister story, which was a welcome change from the usual sales pitches of other manufacturers.

“My favorite part of the job is interacting with all the different people, from ET nurses and patients to marketing managers from other parts of Europe,” added Clementine. “They all love to share their stories and I love sharing mine.”



*“Hollister always focuses on the customer first,
rather than just selling the product.”*



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Announcements/What's New

Puerto Rico Hosts IOA Congress

Representatives from over 35 countries will gather August 7-12 at the lovely Fajardo Inn in eastern Puerto Rico for the IOA 12th World Congress. This year, instead of an exhibition, manufacturer representatives will each give a special 10-minute presentation and sponsor a guest speaker. Hollister is pleased to welcome Susan Stelton, Vice President of WCET. Special programming and events are planned for the attendees, and the member country delegates will elect new officers.

In addition to informative sessions, delegates will enjoy a welcome reception around the Bamboo Beach pool, an 18-hole putting course, karaoke and a tour of historic San Juan. A first-time international auction will feature an item from each of the countries represented.

"World Congresses are very special events. I have met people from literally around the world, including those from underdeveloped countries," said Di Bracken, outgoing IOA President. "Meeting people renews my faith in the work I've done, and will continue to do, on behalf of the organization."

