# Secure Start

A Quarterly Newsletter for People with Ostomies

# **Big News for Our Little Customers**

Hollister kicks off an upgraded line of kid-friendly products

Is the pouch hard to put on? Does it feel weird? If people hug you will they break the pouch open? These questions and more are answered in a new coloring book developed by Hollister with the help of 12 inquisitive kids. This is just one of many exciting new offerings designed expressly for children.

Joy Boarini, Sales Education Manager at Hollister Incorporated, listened to customers and worked with product development and marketing to help bring about these much-needed changes.

stickers are more fun than ever

Updated Pouchkins,

"We talked to clinicians, found out what they needed and applied our new technologies for this very special population. You shouldn't have to be a certain size to get the full benefit of our products," Joy explained.

Upgraded **Pouchkins** Pediatric Pouching System feature many new innovations focused on comfort and ease. These include **SoftFlex** standard wear skin barriers, an exclusive floating flange, **Lock 'n Roll** closure, **ComfortWear** panels and filters.

Redesigned Pouchkins stickers are more fun than ever. You'll find the Pouchkins character playing soccer, hula hooping and more. Hollister has even added space to the sticker for pouch change times and dates, which is especially helpful in the hospital and in the NICU.

And that's not all. The Hollister quality and attention to detail extend to support materials as well. The ever-popular Shadow Buddies "Ostomy Buddy," designed with a stoma, now has an embroidered face and ears. Available exclusively from Hollister, it's packed with a Hollister Premie Pouch. The What's Right For My Baby booklet is being updated and translated into Spanish.

Some things have not changed. Joy Boarini and her staff of Clinical Education Specialists are always available to talk to new parents. "We help take away some of the anxiety of dealing with the ostomy by giving them

information and quality products," Joy said. "This allows parents to focus on what's really important—their new baby."

Want a coloring book or Pouchkins stickers? Call Hollister Consumer Programs at 1.800.323.4060, option 3.

New coloring book helps kids understand ostomies



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### Resources

# United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826 info@uoaa.org www.uoaa.org

### Wound, Ostomy and Continence Nurses Society (WOCN)

1.888.224.9626 www.wocn.org

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

1.800.932.3637 or 212.685.3440 www.ccfa.org



### **Personal Profile**

# **Walking in Their Shoes**

Aimee Frisch is a young adult role model, advocate and peer



When Aimee Frisch talks about the time her dog Molly ran off with her pouch clip, the room explodes with laughter. Her openness and sense of humor are not the only things that make Aimee the perfect facilitator for a Milwaukee support group for young adults with ostomies. She's actually one of them.

At 29 she has undergone three major surgeries due to indeterminate Crohn's colitis and lives with a permanent ostomy. Though she went through some pretty scary times, she managed to plan her wedding, get married and change jobs. Luckily she found another young woman with an ostomy she could talk to, and later joined the young adult group she now facilitates with her friend Julie.

"I feel it's important for young people to know that there are other people their age who can help them through their self-image issues and completely understand their needs," Aimee explains. These issues range from clothing, school, intimacy, pregnancy and appropriate pouches for a young active lifestyle. Aimee recommends the **New Image** Two-Piece Pouch with **Lock 'n Roll** Closure from Hollister and loves the Closed Mini-Pouch for swimming, canoeing and camping.

Aimee also helped create a website and CD for young adults with ostomies that she distributes to product reps, doctors and WOC Nurses. "It's harder to reach young adults, and even harder to reel them in. You have to come up with something that they can relate to," Aimee adds.

In addition to her work with young adults, Aimee is also a case manager for a nonprofit agency, works as a certified nursing assistant, and plans to become a WOC Nurse and a mom! "I never dreamed of being a nurse before my ostomy, but it has changed my life forever. Now I can take my experiences and use them to be an advocate for others and really make a difference," she says. The difference is that Aimee can walk in their shoes and is willing to go the extra mile.

# My Mommy Poops Out Her Tummy

Motherhood with an ostomy takes support and a sense of humor

By Brenda Elsagher

One day our whole family went to the clinic. I was having hemorrhoids examined, my husband was having a mole removed, my five-year-old son, John, was being tested for strep, and my three-year-old daughter, Jehan, was along for the ride. Some families go to the zoo.

My appointment took the longest, and two hours later the doctor said, "I'm almost 100% sure you have cancer of the rectum." I was a 39-year-old mom trying to comprehend the horror of what he said while my children played at my feet. Almost immediately I told the doctor, "You have to make me well. I intend to dance at my children's weddings."

Three weeks later I had my rectum removed, a hysterectomy, an appendectomy, vaginal reconstruction and a permanent colostomy. Couldn't they throw in a complimentary tummy tuck while they were at it? My children motivated me to get through the painful healing process as did the thought of my husband ending up with a better second wife. Many days I put on clothes and a smile when it was the last thing I wanted to do.

From the moment we knew where we were headed, we lined up support. One friend took calls from church friends who delivered meals every other day for five weeks. Another came over on the

days my husband was at work. Many people did house cleaning and sent prayers, flowers, gift certificates and notes. My co-workers even picked up some of my work and helped run things smoothly in my absence.

> We talked simply but directly with our children about why Mommy couldn't hold them for a while and the reason they had to be careful around Mommy's tummy.

"Colostomy" and "pouch" became as much a part of my children's vocabulary as "Fun with Dick and Jane."

My children can't remember a time when I didn't have an ostomy. When they were young, I popped in a video for them to watch in my bedroom as I spent an hour irrigating in the adjacent bathroom. Irrigation isn't for everyone who has a colostomy, but for me it became an odd blessing.

As my confidence with my ostomy and my children grew, I would allow them to play in the yard while I was in the bathroom. I always kept the window open so I could talk to them below. One day I overheard a neighbor child ask, "Where is your mommy?" My son answered, "She's in the bathroom. My mommy poops out her tummy." We all laughed hysterically.

And years later as I rushed to get my kids off to school, something wasn't adjusted right. I was just about to pour their milk, when...splat! A pile of poop sat on the kitchen floor. My son looked at it and said, "Gross."

Having small children while dealing with an

Brenda and her family in the '80s ostomy is not only possible, but it helped me focus on something besides myself. My children see me as a busy, strict, funny, loving, crazy mom who happens to live with an ostomy. They are teenagers now and not bothered by my ostomy at all. These days they're only concerned when my wallet is empty.

Brenda Elsagher is a national keynote speaker, author, comic and person with an ostomy for 10 years. Her latest book, I'd Like to Buy a Bowel Please! is available at www.livingandlaughing.com.







### **Talking Points**

# **New and Improved Pouchkins Pouching System**

### Learn the ABCs of these innovative designs and how they can be reimbursed

**Pouchkins** Pediatric Pouching Systems have been updated with many of the innovations that customers appreciate in our adult ostomy products. **SoftFlex** standard wear skin barriers are proven safe and comfortable for the pediatric population. The exclusive floating flange means no pressure on tender tummies and now features the low-profile and lightweight floating flange design. For maximum versatility, all skin barriers in Pouchkins line come without a starter hole. **Lock 'n Roll** closures and filters make these updated designs even more versatile.

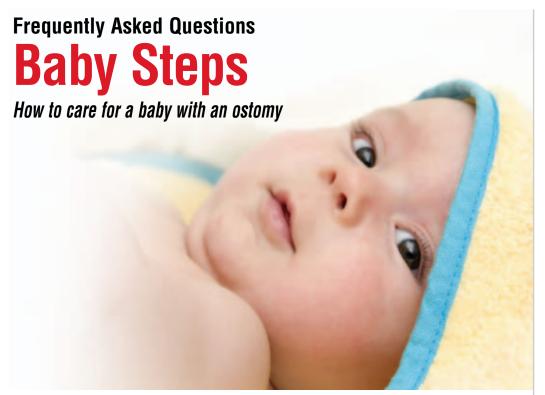
Because these products are designed for the pediatric population, there is no overarching insurer (like Medicare) to reference for fee schedule amounts or quantity limitations. Each insurer will need to be consulted separately. The table below offers all the relevant information, including the product code, product description and HCPCS code.

Most of the HCPCS codes are self-explanatory. However, it should be noted that for products 3777 and 3778, two HCPCS codes are required for billing. These products come as two separate pieces (the barrier is not attached to the pouch). For that reason, one code is needed to describe the pouch and another to describe the barrier that's included in the package. Got questions? Contact your

local Hollister representative.



Product Code	HCPCS Code	Product Description
3777	A5052 A4362	Premie Closed (or drainable) Pouch with detached Cut-to-Fit SoftFlex flat skin barrier. No tape, no starter hole, no filter.
3778	A5062 A4362	Newborn Drainable Pouch for use with or without drain valve with detached Cut-to-Fit SoftFlex flat skin barrier. No tape, no filter.
3796	A5061	Infant One-Piece Drainable Pouch with flat, SoftFlex skin barrier attached. No starter hole, no tape, no filter, with Lock 'n Roll closure.
3797	A5071	One-Piece Infant Urostomy Pouch with flat, SoftFlex skin barrier attached. No starter hole, no tape.
3761	A4414	Infant/Child Flat, SoftFlex Skin Barrier for use with two piece system (green). No starter hole, no tape.
3799	A5063	Infant Drainable Ostomy Pouch without filter with Lock 'n Roll closure (green). Part of Two-Piece system.
3795	A5061	One-Piece Child Drainable Ostomy Pouch with flat, Cut-to-Fit, SoftFlex skin barrier attached. No starter hole, no tape, with filter and Lock 'n Roll closure.
18292	A4425	Two-Piece Child Drainable Ostomy Pouch with filter and Lock 'n Roll closure.
18402	A4432	Two-Piece Child Urostomy Pouch.



Many adults are surprised to learn that some infants need to have an ostomy in the newborn period. This can be somewhat overwhelming for parents at first, but good information, support and the right products can make this situation more manageable. Here are some common questions asked by parents of babies with ostomies:

### Q: Can I breastfeed my baby?

A: Certainly. Breastfeeding offers many advantages for both baby and mom.

### Q: Sometimes my baby's stoma is not red. Is that normal?

A: The stoma is usually red and moist, **but** sometimes when a baby cries, the stoma becomes almost white. If the color change is temporary – less than a few minutes – it is normal.

# Q: My child has gotten older and has now started pulling his pouch off. What can I do?

A: Children are naturally curious about their bodies and things around them. The pouch is no exception! It helps to dress your child in a one-piece outfit, even for naps. This can deter his or her exploration of the pouch. A few toys in the crib can also help to satisfy his or her curiosity.

# Q: My baby's pouch used to stay on longer. Is there anything I can do?

A: As a baby crawls, scoots and pulls himself or herself up, there will be additional stresses placed on the pouch seal. This is all normal activity and should not be discouraged. Also, teething can sometimes cause the skin barrier to erode more quickly. This is frustrating, but normal. He or she may need a larger pouch or a different type of skin barrier. Your child's WOC nurse may have some tips to improve the seal.

### Q: Is it normal for the pouch to fill with air all the time?

A: Much of the gas in the pouch is the result of swallowed air. Infants suck on many things, which causes this effect. If the gas is a problem for the pouch seal, a pouch with a filter may allow the gas to escape continuously.

### Announcements/ What's New

### Get Your Guts in Gear Ride a Personal Success

Congratulations go out to the 100 riders and support staff and our very own Secure Start columnist, Brenda Elsagher and Mark Kennedy, Senior Product Manager, Ostomy, who completed the Get Your Guts in Gear Ride for Crohn's & Colitis in the Pacific Northwest. The 210-mile ride took place August 18-20 just north of Seattle along the beautiful coast of Washington state. Though they returned home with a few aches and pains, they both found it quite rewarding to meet their fellow riders (many of whom have or have had ostomies) who are all so passionate about the need to discover new methods of managing and, ultimately, preventing IBD. The next ride is in 2007. Care to join them? For more information go to www.ibdride.org.



Brenda Elsagher, Judy Pacitti (Ride Director) and Mark Kennedy

Support and the right products can make the situation more manageable





Screaming on the Giant Dipper Roller Coaster, roasting s'mores over a campfire and rollicking in the ocean. This is just a glimpse of the fun had by 98 tweens and teens in San Diego July 8–12 at the Youth Rally Committee, Inc. (YRC) 2006 Youth Rally.

Attendees from 11 to 17 years old traveled from sea to shining sea to reconnect with old friends and meet new ones. Many of them were sponsored by their local UOAA chapter and had the time of their lives.

Though the focus was on fun, 10 WOC nurses were on hand to assess stomas, review catheterization techniques and make sure all were using appropriate products. Heather Budorick, Clinical Education Specialist at Hollister Incorporated, attended.

"Just seeing that there are so many kids like them helps boost their sense of well-being and makes a real emotional impact," Heather explained. "And the bonus is to learn about other product options."

The fun continued all week with a "Blast from the Past" '70s game show hosted by the WOC nurses and announcer Wink Martindale (aka Paul Hasting, president of the YRC). Excitement included educational games and exciting prizes. The rally culminated in a Mardi Gras dance and touching graduation ceremony.

Though everyone enjoyed the events, many attendees enjoyed their unstructured time the most. They spent every moment of it talking to their peers, networking and planning for next year.



# Someone You Should Know at Hollister Mike Cherry

New Product Development Engineer, Ostomy

The best part of Mike Cherry's job is seeing new products in action. To test the upgraded **Pouchkins** products, he shadowed a WOCN at Children's Hospital Los Angeles and met 50 babies and children with ostomies.

"My favorite was little Anthony who was only two weeks old and already using our products. With the help of the nurse and his mother, we were able to see how our upgraded designs worked." Mike explained. This hands-on approach begins at concept. He creates specific teams for specific products and guides them through concept and design to production and customer approval. "My job is all about communication, "Mike chuckled.

Mike brings 30 years of experience to his position and has helped develop products from intraocular lenses and cardio-pulmonary oxygenators to cancer treatments. He admits that his five years

with Hollister Incorporated have been his most satisfying.

"Like our motto says, together we make a difference. It took a diverse team to develop the new Pouchkins products—from manufacturers in Ireland to nurses and parents in Los Angeles, to our marketing team in Libertyville. We worked together and we did make a difference."

### **Hollister Reaches Out**

# **YODAA Rocks Cleveland**

### The Young Ostomate & Diversion Alliance of America conference blends support and fun

More than 50 young adults descended upon Cleveland this past August, and the town will never be same. Hollister was proud to join them as a gold-level sponsor of the first standalone conference of the Young Ostomate & Diversion Alliance of America (YODAA).

One of the week's highlights was the keynote speech by 25-year-old Jodi Weatherton, star of the MTV reality series *World/Road Rules Challenge*. She currently has a J-pouch but previously had an ileostomy. Jodi described her teenage battle with Crohn's disease and how now she never lets her J-pouch slow her down as she literally travels all over the world.

Mark Kennedy (Senior Product Manager, Ostomy) and Manish Gupta (Senior New Product Development Manager, Ostomy) from Hollister Incorporated conducted an intensive focus group and manned a busy product exhibition booth called "Pimp My Pouch" based on the popular MTV show with a similar name. The new **Adapt** Barrier Ring was a favorite on the scene.

Best of all, the opportunity to relax with other young people who have had similar experiences was very inspirational for all.

As one first-time attendee put it, "I was surrounded by incredible, strong people, whose stories inspired me as well as made me cry. I felt so comfortable and free. I didn't worry about 'the bag' and felt completely normal and alive. On top of it all...I just had a really good time! I can honestly thank all of you for helping me see that 'living life' has nothing to do with where or how you go to the bathroom."

YODAA is affiliated with the UOAA and is dedicated to providing education, information, support and advocacy to young adults 18 to 35 years of age who have had or may have intestinal or urinary diversions or alterations.

Interested in becoming a member of YODAA? Please contact Kristin Knipp at yodaa@uoaa.org or call 440-231-0912. You can also visit the YODAA discussion board at www.uoaa.org.

"I was surrounded by incredible, strong people, whose stories inspired me."

—A first-time conference attendee



Mark Kennedy, Julielyn Gibbons, Kristin Knipp and Manish Gupta





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