UOA hosts another “winning” conference

More than 500 people with ostomies, as well as many of their friends and relatives, made the trip to Louisville, KY, for the United Ostomy Association (UOA) annual national conference in August.

In keeping with the elegance of Kentucky horse country and the excitement of Churchill Downs and the Kentucky Derby, the theme for this year’s conference was “Join UOA in the Winner’s Circle.”

When they were between sessions, Hollister invited all participants to make themselves at home in the comfortable sofas and chairs in the company booth in the product exhibition area. As they relaxed, visitors learned about the newest Hollister products, including Premier one-piece pouches with integrated filters and Adapt Lubricating Deodorant.

They also received free copies of Brenda Elsagher’s book, If the Battle is Over, Why am I Still in Uniform? — which Brenda was on hand to autograph during most of the event.

One lucky visitor got an additional reward by stopping at the Hollister booth. By answering questions in a survey about Adapt Lubricating Deodorant, that visitor won a trip to next year’s national conference in Anaheim, CA.

Join us — and that winner — at next year’s UOA national conference, August 3-6, 2005, in Anaheim.

For more information on the conference, please consult the UOA’s Web site at www.uoa.org. For more information on any Hollister product or service, please visit www.hollister.com or phone 1-800-323-4060.
When Bob and Barbara Miller were taking 12-year-old Sindi Perdomo from the airport to their home in Waynesville, OH, in June, the Honduran girl was talking a mile a minute.

Unfortunately, she was speaking in Spanish.

“Bob said ‘No hablo espanol,’ and she looked at him and said ‘Yo no hablo ingles,’” says Barbara Miller. “Then she burst out laughing. She just assumed we spoke Spanish.”

The Millers are host parents for Children’s Medical Missions (www.medical-missions.org), a not-for-profit organization that helps seriously ill children come to the United States for medical treatment.

Sindi was brutally raped when she was 9, in an act so violent it left her internal organs damaged. Surgeons in Honduras attempted to repair the damage, but it became evident that only a colostomy would allow the damaged sites to heal.

The ostomy, which is expected to be temporary, was performed at Lima Memorial Hospital in Lima, OH, but there were some challenges to overcome. For one thing, Lima’s pediatric ostomy patients usually are sent to Toledo or another larger city for treatment.

“I do ostomy care at the hospital, but I’d never had a pediatric ostomy patient — and certainly not one who doesn’t speak English,” says Nancy Gutman, WOC (wound, ostomy, continence) nurse. “I had an interpreter the day after the surgery, but I wasn’t getting very far in helping Sindi understand.”

Although Sindi’s family had prepared her well for the surgery, “When she first saw her stoma, she just cried and said she was ugly,” says Mrs. Miller. “Two days later, she had a lady take a picture of it so she could take it back and show it to her mother.”

Part of the turnaround was due to a Shadow Buddies doll.

“Sindi wouldn’t let me touch her on the first visit, so I put a pouch on the baby and let her help me,” Gutman says. “That’s really how I taught her to care for herself.”

Hollister supplies more than 1,500 dolls and miniature pouches a year for children who are having ostomies.

Another problem was finding the right pouch. Pediatric pouches were too small; adult pouches too large.

“I called Jane Gesenhues, a sales specialist at Hollister, because I knew I wanted to use New Image pouches on Sindi,” Gutman says. “It’s a nice pouch for her, because of its low profile and size. Jane sent enough to last the six weeks until the ostomy is expected to be reversed.”

Hollister also has helped with information, says Mrs. Miller, adding that she and her husband had never seen an ostomy before, either.

“Sindi has been through so much, but she’s really a trouper. And Hollister is an invaluable resource for information, as well as supplies,” she says.
Here are some suggestions that might help:
• Ask friends to spend time with your spouse/partner. They can go to a movie, dinner or just for a walk, but should allow time to talk over concerns and ask if they need anything.
• As a couple, get support from groups like the United Ostomy Association. At their national conferences they address this issue. They also have literature they can send to you. Your local chapters often encourage partners to attend “rap” sessions and often have groups for partners of ostomates to meet, compare notes, and offer each other understanding. Just as no one really understands an ostomy unless they have one, the same thing applies to partners.
• For some people, professional counseling might be appropriate.
• Hollister has nurses on staff to offer support and information.
• It is a good idea for partners to know what medications and products each uses in case of a medical emergency. Write them down someplace that is easy to find.

My husband is a master of puns, almost to the point of agony (mine). At the time of my illness and surgery, things got very serious, very fast. He didn’t make a pun for almost two years. As much as they had tormented me in the past, I now longed for them, because I’d know his heart was lighter.

Things take time and I am happily being assaulted with puns these days.

Prior to surgery and the night before my big CAT scan (a test that would reveal if the cancer had spread), I was lamenting to my husband as I tossed and turned, “What if it’s in my liver?” With a straight face, he replied, “Oh, liver alone.” It was so stupid it made me laugh and I fell fast asleep.

I hope you all have partners that like to torture you with their humor. When they see you laugh, it’ll help them to lighten up, too.

Brenda Elsagher is an ostomate, comic, national speaker and author of the book, If the Battle is Over, Why am I Still in Uniform? She resides in Burnsville, MN. Please direct “Ask Brenda” questions to her at BMElsagher@aol.com.
When the Colostomy Society of New York was formed more than 50 years ago, doctors thought that colostomy and ileostomy were different enough that support groups for those who had had them should be kept separate.

"Now we know differently, of course, and we meet jointly with the Ileostomy Association of New York, although the two organizations remain separate," says Marge Scannell, president of the Colostomy Society and regional coordinator for about 62 chapters of the United Ostomy Association (UOA) in New York, New Jersey, Pennsylvania and Delaware. "We have about 150 members in each group, and I work with Diane Watkin, acting president of the Ileostomy Association, on programming, answering questions and meeting the needs of ostomates in our area."

There are eight joint meetings a year, attended by approximately 50 members.

“Our purpose is to give comfort and support to members, as well as to offer the support new ostomates need to adjust to this way of life,” says Scannell. “We have a wonderful rapport with the Visiting Nurse Society of New York, although all the new healthcare privacy rules have impeded that a little. They are no longer allowed to give us the names of patients."

Instead, hospital WOC (wound, ostomy, continence) nurses and social workers and the visiting nurse association give patients information on the Colostomy Society and encourage them to call for information and support.

Although Scannell visits hospitals in Manhattan and the Bronx (the areas the society covers), “People are getting sent home so quickly now, most of our visits are done either over the telephone or at their homes.”

Too often, she says, people go home without being told about the Colostomy Society. Left to cope with their ostomies on their own, they may become depressed.

The Yellow Pages, a link through the UOA Web site and eight newsletters a year are among the ways the organization reaches out. Another is an annual roundtable health fair, where Hollister is always a notable presence.

“Hollister representatives are always there to answer questions about supplies and new systems, as well as general ostomy care,” Scannell says. “And they'll do meetings for us, whenever we ask. They're wonderful.”

Over the next five years, Scannell wants to increase outreach and awareness efforts.

“I want to start groups for parents of ostomy children and for younger people with ostomies within our chapters,” she says. “And I want to increase public awareness about ostomy. The media ignores it because of the subject matter, and we need to change that.”

Tell us your story

People with ostomies have experiences that others can learn from. Won’t you share yours? Whether you run marathons or just stay busy running your normal active life, we’d love to hear from you. If you’re willing to share your story with others, please e-mail Mark Kennedy at mark.kennedy@hollister.com or Barbara Conti at barbara.conti@hollister.com.
When the Hollister office in Milan, Italy, did a survey of new ostomy patients at the beginning of 2004, the results were not encouraging. Only five of 350 respondents felt ready to care for their ostomies when they were discharged from the hospital.

“It appeared there was some room for improvement,” says Maria Luisa Valsecchi, marketing manager. “So we launched a program with the Associazione Italiana Operatori di Stomaterapia (enterostomal therapy or ET nurses association) to provide educational tools and information to help people become more independent, before they are discharged.”

That program, called the Sfera Project, is ongoing. It, like the Moses Project that ran from 1999-2002, is a Hollister effort that offers guidelines in areas such as pouch care, food, irrigation and other subjects. It is designed to help make life as comfortable and simple as possible for people with ostomies.

The programs complement the Hollister-sponsored nurses’ training that began when the Hollister office opened in Milan in 1995. About 50 nurses each year attend basic to advanced training programs.

“All Hollister programs are credited by the National Healthcare Ministry,” says Valsecchi. “In fact, our Moses Project set a standard in stoma care, because all the information has been clinically proven through research based on more than 3,500 case studies by 150 stoma care professionals.”

The 42 associates in the Hollister Italian organization, led by General Manager Cristina Loguerchio, serve all of Italy, where there are an estimated 50,000 people with ostomies.

In addition to ensuring that each patient has access to quality Hollister supplies and high-quality educational materials, the office maintains a toll-free line for people with ostomies and nurses to call in with questions.

“That is the real core of our link to patients,” says Valsecchi. “Two dedicated associates answer all the calls. They determine patients’ needs and, when appropriate, send packages customized with samples, leaflets, instructions and other materials for that particular caller. Another associate does follow-up calls to be sure patients who contacted us are satisfied.”

During an average month, this dedicated service receives up to 450 calls from patients and nurses. They send 320 parcels a month, and have established a database with more than 10,000 names. Because Italy has very strict privacy laws, patients are contacted only when they have given advance permission in their initial contact.

“The toll-free line also provides references for patients who are looking for support groups,” Valsecchi says. “Most patient support groups in Italy are regional, and we can help people find them. Our purpose is to enhance the quality of life for people with ostomies, and we work hard to do that. We track complaints and other opportunities for improvement, because we want to be sure our customers and clients are satisfied. Anything that we can address, we do.”
When choosing an ostomy pouching system, you can select either a one-piece or a two-piece system. With a two-piece pouching system, the pouch and the skin barrier are separate pieces that allow you to change the pouch without removing the skin barrier from the skin. To connect the two, some type of flange is used to secure the pouch to the skin barrier. The beige, low-profile flange of Hollister’s New Image Two-Piece system provides security, discretion and comfort through its unique floating flange design.

**Security**
The most important function of the flange is to secure the pouch to the skin barrier. Security is essential to prevent unexpected leaks. As you connect the New Image pouch to the skin barrier, you will hear a series of clicks as the two parts of the flange engage. The floating flange allows you to place your fingertips under the flange on the skin barrier, rather than pushing directly against your skin. By pinching the pouch and skin barrier together around the entire flange, you will securely connect the system, and it will stay connected until you remove the pouch.

**Discretion**
The flange on the New Image system is lightweight, flexible and thin: all qualities that help make it easy to conceal beneath your clothing. This flange is thinner than any other mechanical flange on the market.

**Comfort**
The floating flange on the New Image system allows the skin barrier to bend more easily. The unique design means the flange floats above the level of the skin, rather than pushing into your body as you move. The advantage of a floating flange is particularly evident when you attach the pouch to the skin barrier. You can attach the two pieces without pressing against your tummy — a welcome change if you have had recent surgery and a tender abdomen.
New Image Pre-Sized Skin Barriers with Floating Flange

Hollister now offers a full range of New Image flat, pre-sized skin barriers that feature our unique floating flange. If you are using a cut-to-fit skin barrier, we encourage you to try the ease and convenience of pre-sized options.

The floating flange allows you to put your fingertips under the flange, providing additional support, while the pouch is attached to the skin barrier. Whether you prefer your skin barrier with or without a tape border, there is a New Image Pre-Sized Skin Barrier with Floating Flange in your choice of either Flexextend extended wear or FlexWear standard wear barriers.

These new products were introduced November 1, 2004. They will replace pre-sized New Image skin barriers with stationary flanges, which will be discontinued at the end of June 2005.

For more details, please call Hollister’s Customer Service Center at 1-800-323-4060 or ask your supplier.

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Reimbursement: How much is covered?

by Linda Aukett – Chair, Government Affairs Committee, United Ostomy Association

For people with ostomies who are on Medicare (and increasingly for those with “managed” health insurance), one frequent question is “How many products am I allowed?”

With a few exceptions, the answer for single-wear products is in Medicare’s Usual Maximums, which provide for the following each month:

- Up to 20 drainable pouches
- Up to 15 urinary pouches
- Up to 60 closed pouches
- Up to four irrigation sleeves
- Up to 15 skin barriers with flange

It is a good idea to be sure there is a statement in your doctor’s file concerning the number and type of ostomy supplies you need, because your supplier will be asking your doctor for a statement of need, as part of the Medicare approval process.

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Hollister Incorporated has skilled customer service staff to assist you with questions about our products. Additionally, we have nurses who specialize in wound, ostomy and continence care (WOC nurses) who provide support and information. Some of the most frequently asked questions include:

**What is a flange?**
A flange is the part of a two-piece pouching system that connects the pouch to the skin barrier. Flange designs differ from one brand to another. Some flanges attach using a plastic mechanism and others rely on adhesives.

**Why would I want a floating flange?**
With a floating flange, you will be able to more easily attach the pouch to the skin barrier, the skin barrier will be more flexible on your skin, and there will be no pressure on your abdomen when attaching the pouch.

**When I hear the flanges click, does that mean the pouch is securely attached?**
NO. The "clicks" let you know that you are aligning the flanges correctly. You will hear multiple "clicks" before the flanges are secure. One click is not enough.

**Is the floating flange only for in the hospital?**
NO. The unique floating flange is ideal in the hospital, because it means that there is no pressure on the tender post-operative abdomen when the flanges are attached. However, you can continue to use the floating flange after returning home. It is secure, offers great flexibility, and some people find it easier to use, if they can get their fingers under the flanges for attachment.

If you are among the 10 percent of those with ostomies who need more than the products allowed, your dealer will need a letter from your doctor explaining the medical reason for the need. Your supplier will keep this letter on file in your records and will give a short summary on the electronic claim he submits for you. If you are working with a WOC nurse, be sure the nurse puts recommendations in writing to your doctor, so they will be in your file when your dealer requests a statement.

For people not on Medicare, the issue is less clear. Some health insurance companies follow the Medicare guidelines, but others do not; you may find there is a limit on the number of ostomy products that will be reimbursed. This limit often includes doing business with their "preferred" dealers.

Remember, though, that when you are paying out of pocket, you can shop anywhere – and it makes sense to find the lowest retail prices. While manufacturers often mention a suggested retail price, it pays to shop around. A number of national mail-order companies have toll-free phone numbers and Web sites, so use all your shopping skills to find what you need at the best price.

Over the past several years, the United Ostomy Association has worked to improve the reimbursement situation, and would be happy to help you, when problems arise. Please contact us at 1-800-826-0826.