

Secure | Start

A Quarterly Newsletter for People with Ostomies

Friends For The Long Run

The New Secure Start Community Program from Hollister provides ongoing support

Have you had your ostomy for many years but still have questions and concerns from time to time? Were you a member of the **Secure Start** Discharge Program right after surgery and now miss the one-on-one support? Hollister introduces an exciting new program that's tailor-made for you. The new **Secure Start** Community program provides personalized support, encouragement and education for those who want to continue improving their quality of life.

"We've learned so much about providing support through our **Secure Start** Discharge Program that we wanted to extend that support," explains Linda Blackwell, Director of Consumer Programs. "Especially to those who may not know where they can go to get their questions answered."

The **Secure Start** Community program provides a valuable support system. Members are assigned a personal advocate who will be available to answer questions and suggest exciting opportunities. If interested, members may receive a sneak peak at products before distribution; ideas for connecting with other people with ostomies; and the chance to partake in clinical studies, marketing campaigns and quality of life studies. If you're not interested in additional opportunities, you can opt out and a computerized personal profile will keep track of your preferences as well as the activities, samples and information your advocate has shared with you. Upon joining the program, members will also receive a welcome Carry All, personalized identification card and travel alert card. This valuable travel card, which explains your need to wear a pouching system, was designed to save time and prevent potentially embarrassing questions at airport security checkpoints.

"The sole purpose of Hollister is to improve quality of life and to ensure unconditional customer satisfaction," concludes Linda. "The **Secure Start** Community program is another opportunity to give more of ourselves to the people who mean so much to us."

Want to join the **Secure Start** Community program? Simply call the Consumer Help Line at 1.888.740.8999 and a Consumer Representative will welcome you into the Hollister family for the long run.



Announcements/What's New

July Youth Rally to Swarm San Diego

Young people are anxiously awaiting the coming of summer when they will join old friends and make new ones at the Youth Rally at San Diego University, July 12-17. The Youth Rally is a summer camp that provides a non-threatening environment where adolescents between the ages of 11 and 17 can find education, support and friendship. Activities will mix education and fun, including trips to the beach and an amusement park, rap sessions, skits and a closing dance. The Youth Rally is organized and run by the Youth Rally Committee, a not-for-profit organization dedicated to inspiring campers to function as independently as they can. Hollister is proud to be a sponsor of this life-changing camp. Know a young person who wants to have a summer to remember? There's still time to join! Go to www.rally4youth.org right now!

Get Your Guts in Gear This Year

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 6-8, the Seattle-area ride is August 1-3 and the Texas ride is October 17-19. 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 or crew member! For more information, go to www.ibdride.org.

JOIN
THE SECURE
START
COMMUNITY
PROGRAM

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General Information

Hollister Customer Care
1.888.740.8999

Call to subscribe to
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1.888.740.8999

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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)
1.800.932.2423 www.ccfa.org

Editor's Note: In our Personal Profile of J.A. Pacitti in the Winter 2007 issue of *Secure Start* newsletter, we erroneously stated that IBD stands for "irritable bowel disease". We apologize for the error.

Personal Profile

Lessons in Courage

Bret Cromer and Youth Rally campers inspire each other to live life fully



Bret Cromer and psychedelic campers at a past Youth Rally at San Diego State University

When Bret Cromer had ostomy surgery as a result of Crohn's disease at age 16, his family and friends rallied. They decorated his hospital room with ski posters, besieged him with funny movies and his younger brother took over his lawn mowing business.

"The ostomy offered me a chance to be a healthy teenager again," explains Bret. "But the recovery took a long time and I relied on my ET nurse and members of my local ostomy chapter to really understand what I was going through."

Bret is employed as the Director of Business Development for a Chicago-based company and is President of the Ostomy Support Group of DuPage County. But he didn't find his true community until he met a young man who challenged him to go to the Youth Rally, a not-for-profit summer camp for adolescents between 11 and 17 with bowel or bladder dysfunction. The camp is partially sponsored by Hollister and other manufacturers.

"He insisted I go as a counselor because I didn't get to go as a kid, and it changed my life," Bret continues. "Those kids have way more courage than I had and teach me over and over again that it doesn't matter that you have an ostomy—you're still a person."

Six years later, Bret is actively involved with the Youth Rally as a counselor and member of the recruitment committee. Their goal is to support the young people and help them become confident young adults despite their medical obstacles.

"My favorite thing is seeing a shy 12-year-old open up when he or she meets someone with the same diagnosis," Bret added.

After five days of fun activities, educational sessions and peer support discussions, the campers become like family and return year after year to reconnect. And so does Bret, who has become a real family man since he and wife, Kimberly, have welcomed Hayden Marshall into the world.

Pass the word! The next Youth Rally is July 12-17, 2008, at San Diego State University. Go to www.rally4youth.org to get in on the fun.

Ask Brenda

Building Community

Brenda uses humor and friendship as the bricks and mortar

By Brenda Elsagher

When I first had my colostomy, I reached out to my local ostomy support group. They understood what I was going through and gave me tips and suggestions. This community talked about a taboo subject, even during dinner!

In 1996, when I attended my first ostomy support meeting, I learned there were other kinds of ostomies and many bowel and bladder diseases. I saw that I was part of a larger community of people with similar but different issues. This group extended to a national level with the United Ostomy Associations of America. *The Phoenix* magazine, internet blogs and chat lines—even this newsletter—help us share common experiences.

Not a week goes by when I don't hear from someone who has received one of my books, read this newsletter or viewed my website. One of them even gave me a great tag line for my comedy routine. When Kathleen Spencer of Rowlett, Texas heard the old joke, "It's not so bad having a colostomy; I just can't find shoes to match my bag" she blurted out, "You can find shoes—they just look like crap!" I must admit she didn't use the word "crap," but with her permission, I have enjoyed using her joke many times. Thanks, Kathleen!

I also hear from Tim Warmouth of Champaign, Illinois from time to time. He was a floor refinisher and had to retire early because of Multiple Sclerosis in 1990. He doesn't let his ostomy or wheelchair stop him from enjoying his newfound passion for painting. The first day he started though, he threw the canvas in the garage out of frustration. The next day he tried again. It didn't come easy, but with patience and persistence, it paid off.

"Oftentimes, I think creativity comes out of adversity," says Tim. "I was too busy trying to be 'successful' and didn't take the time to be creative." Many of us can relate to that, Tim!

I have also enjoyed talking to Joy Starratt of Middletown, Connecticut who has an ileostomy due to ulcerative colitis. A former therapist, she now keeps busy as a docent at the local museum and is a master loom-weaver. She has been amazingly upbeat, even after her recent chemotherapy. I enjoy hearing about her progress and I appreciate her comments.

I recently got a phone call from Lois Krochmalny of Fairfield, California who received a Mercedes-Benz for Valentine's Day from her husband, Ed, of 49 years.

"My hair is kind of thin," chuckles Lois. "So when I go out in the convertible, I borrow my daughter's pink clown wig!"

She went on to say, "We were reading the last *Secure Start* issue about the Flatulence Brigade and laughed so hard. If you can't laugh about this subject you're in trouble!" Her husband has had a colostomy for almost two years and her daughter Whitney has had an ileostomy since she was a child. Lois wants to find a bumper sticker that reads, "Proud to be a two-bag family."

There are so many perks to writing this column, and I am grateful to Hollister Incorporated for finding another way for us to connect with one another.

Brenda Elsagher is a national keynote speaker, author of *If the Battle is Over, Why am I Still in Uniform?* and *I'd Like to Buy a Bowel Please!* Are you a closet writer? Please submit a funny or inspiring medical story to Brenda for her next book, *Bedpan Banter*. Go to www.livingandlaughing.com for more details. She also welcomes comments and questions at 1.952.882.9882.



"We have all known the long loneliness and we have learned that the only solution is love and that love comes with community." —Dorothy Day



Announcements/What's New

Premier Urostomy Pouches Now in Beige

Premier Urostomy Pouches are now available in beige for increased discretion. The odor-barrier, rustle-free film is quiet, and all pouches (beige and transparent) have **Flexend** extended wear skin barriers. The barriers are available in cut-to-fit and pre-sized, as well as flat or convex. Note that all barriers have a tape border. And with soft, non-woven **ComfortWear** pouch panels now on both sides, you'll experience increased comfort as well.

AF300 Ostomy Filter

Now Available on Premier Closed Pouching Systems

As you may recall from the last issue, Hollister introduced the **AF300** Ostomy Filter, a revolutionary filter designed to greatly improve the quality of life for people with ostomies. We're pleased to announce that the new filter is now available on additional pouches, including **Premier** pre-sized and cut-to-fit pouches.



New Image

1818x, 1819x	New Image Drainable Pouches with Lock 'n Roll
1836x, 1837x	New Image Closed Pouches
1838x, 1839x	New Image Closed Mini-Pouches and Premier Cut-to-Fit

Premier

82325, 82330, 82335	Premier Pre-sized Closed Mini-Pouches
82300, 82400	Premier Cut-to-Fit Closed Pouches
82130, 82135	Premier Pre-sized Closed Mini-Pouches

Chapter Profile

Triple Play

Southeastern Wisconsin members call three support groups home



Wisconsin is known for cheese, beer, the Packers and the Brewers, but for people with ostomies, the Badger State is famous for good old-fashioned friendliness.

"Everyone wants to tell their story, and that's what we do best," explains Tom Huber, President of the Ostomy Support Associations of Southeastern Wisconsin. "Those who have led meaningful lives are encouraged to be there for new members, even if they no longer need the support."

In order to reach more people, the Ostomy Support Associations of Southeastern Wisconsin run three separate groups. Metro Milwaukee's Froedtert Hospital is home for an evening meeting held every other month, run by a social worker as a true support group. Every month, two WOC (Wound, Ostomy and Continence) nurses host a meeting at Waukesha Memorial Hospital packed with manufacturer presentations, visiting doctors and other speakers. And a dynamic young adult group meets every month at the Medical College of Wisconsin to discuss topics such as nutrition, sexuality and pregnancy.

The three groups converge at an annual Christmas party for some Wisconsin-style fun, and a vendor fair is in the works for early summer. In between get-togethers, the 173 members keep in touch via a monthly newsletter edited by Tom featuring helpful articles, an "Ask the Nurse" column and a calendar of events sponsored by Hollister.

To reach new members, the group provides area WOC nurses with a discharge planning folder filled with product and **Secure Start** Program materials, a support group brochure, business card and current newsletter.

Tom and his crew never know whose life they're going to touch; they just know with this much support they're bound to make a mark. Tom received an anonymous letter a few years back that read, "You don't know me, but you really helped me."

"That has always been my inspiration," says Tom. "Our mission is to be out there and help people and I love hearing that we really made a difference."

Frequently Asked Questions

The Consumer Programs Team is There When You Need Them

Our experienced Consumer Programs team receives thousands of calls per month. Most of these are from people with ostomies, some with many years of experience and some who are brand new to the scene. Although the questions are as varied as the callers, there tend to be some common inquiries. Here are just a few:

How do I take care of the skin around my stoma?

A: A general rule of thumb is "less is better." For most people, water alone is sufficient for cleaning. If soap is needed, use a mild one that doesn't leave a residue or film that can interfere with the pouching system adhesive. Things not recommended for routine skin care around the stoma include creams, lotions, powders, baby wipes, alcohol, steroidal medications or ointments. Many people use an ostomy skin prep wipe on their skin. These include ones that remove adhesive residue and others to form a film on the skin. If you use one of these, be sure you understand the difference and use the appropriate wipe.

What do I do about skin irritation?

A: Most people with an ostomy will encounter a skin problem at some time, even if they are very careful. We often hear from people who have tried self-remedies or let a problem persist thinking it will improve on its own. Remember, no skin irritation is

"normal" and if and when you discover you have one, you need to address it immediately. There are many reasons why the skin around an ostomy can become broken. The key is to determine the cause and to treat it appropriately. For example, an antifungal powder is appropriate for yeast but not for skin stripping from tape. Sometimes, you need someone to help you get on the right track or to provide a referral to a WOC nurse.

Sometimes I have to change my pouch more often, why is this?

A: There are many factors that affect wear time, such as consistency of output, humidity, activity, barrier type, skin condition and preparation. Although it is possible that the product is not functioning properly, it is not usually the case. For example, we often hear from people when there has been a change in the weather and it is more humid and/or they are more active. Typical pouch change frequency is twice a week.



Linda Blackwell

Someone You Should Know at Hollister

Linda Blackwell

Director of Consumer Programs

What do I do about skin irritation? How do I increase the wear time of my pouch? Is there a supplier near my home? When

questions like these arise, Linda Blackwell and her team come to the rescue.

"We help people with ostomies manage their environment," explains Linda, Director of Consumer Programs. "We provide product suggestions, samples, dealer referrals, insurance information and reassurance so they can get on with their lives."

The Consumer Programs group is made up of three teams. The Clinical Team consists of WOC nurses who provide clinical education and product training for customers, nurses and hospitals. The Consumer Team answers calls and follows up with customers who have requested product samples. The **Secure Start** team provides personalized support for program members for up

to six months after surgery. Linda is proud of the fact that her group also guides customers through complicated insurance and reimbursement issues.

A native of Cleveland, Linda joined Hollister 27 years ago as a sales representative and has led the Consumer Programs group for the last six years. When not managing her teams at the corporate headquarters, Linda travels the globe to meet with sales representatives, nurses and dealers to establish similar consumer programs. She is most at home, however, when she has a chance to talk to customers personally. Most recently, she spoke to a woman who did not know she could shower with her ostomy and had gone for three months without one.

"A simple outreach to assure her that she could indeed take a shower was monumental to her," Linda adds. "I love living the mission of Hollister to actually improve the quality of life of those who use our products."

The Netherlands

Masters of knowledge, support and compassion



The Hollister Netherlands team at their 2008 kick-off meeting in Geneva

“The way the company works to make a difference in people’s lives makes me proud to work for Hollister.”

Though the Netherlands is only twice the size of New Jersey, it has an expansive heritage. Not only is the country known for brilliant flower gardens, delicious cheese and bike riding, but also for the incomparable works of Rembrandt, Van Gogh and Mondriaan. For the 28,000 people with ostomies, Hollister in the Netherlands has followed suit by mastering the art of knowledge, support and compassion.

Like the Netherlands, the office in Amersfoort is small, consisting of four customer service representatives, one sales manager, two product managers, an educational support manager, a business analyst and four outside sales people. Henry Lowik, Product Manager Ostomy, feels that their size is their strength.

“We are a small group so we can be very personal and learn a lot from each other,” explains Henry. “We share a lot of tears and a lot of laughs and that’s what makes us a very strong team.”

This closeness extends to customers as well. When the team heard about a woman with a urostomy who complained of skin irritation and reduced pouch wear time, they sprang into

action. Upon a home visit, they noticed that she was overusing products, therefore, nothing would stick to her skin. She was using 20 barriers a day and becoming very depressed. After several trials and errors, the **Moderma Flex One-Piece Pouch with Medical Adhesive Spray** under the barrier really made a difference.

“We invested a lot of time, but succeeded in finding a good solution,” added Henry. “The result was a good relationship with the patient and ostomy nurse.”

In the Netherlands, healthcare is quite advanced for people with ostomies, and ostomy nurses are plentiful. Right after surgery, a clinical nurse offers product ideas and support and then a community nurse, who is also well versed in ostomy care, takes over. Apart from the WOC nurses on the Hollister team who provide advice and education, all medical supply companies have at least one or two specialists on board. A standard number of pouches and barriers are reimbursed 100% by insurance companies in the Netherlands.

The National Ostomy Patient Association in the Netherlands is 7,000 members strong, and Hollister is there three times a

year with a well-equipped booth, gifts and product information. As Product Manager, Henry makes it a point to attend meetings and speak to customers whenever possible.

“When you talk to customers you can really understand what they’re going through,” says Henry. “And you can give them practical tips, product ideas and even psychological support.”

Hollister also offers educational programs for nurses and customers, produces a newsletter and has an informative website. Ads in several magazines have proven quite lucrative, but the products and customer support are what draw customers to Hollister again and again.

“The Hollister tag line, ‘Attention to Detail Attention to Life’ really says it all,” concludes Henry. “The way the company works to make a difference in people’s lives makes me proud to work for Hollister.”

Talking Points

2008 Medicare Update

Deanna Eaves, Reimbursement Manager, tracks policy changes in the ostomy community

A new billing year often brings reimbursement changes, and you’re probably wondering how they may affect you. Luckily, the only change in the Ostomy Medicare Durable Medical Equipment (DME) Policy for 2008 was the addition of a new billing code that did not impact Hollister products in any way. The rest of the policy remains the same, so let’s review a couple of highlights.

Medicare’s maximums are outlined in the Medical Policy by their billing codes. As a general rule, the published maximums include the following:

- | Ostomy Medicare DME Policy for 2008 | |
|-------------------------------------|---------------------------|
| • 60 closed pouches | • 4 oz of stoma lubricant |
| • 20 drainable pouches | • 31 stoma caps |
| • 20 urinary pouches | • 4 oz of paste |
| • 20 standard wear skin barriers | |

There are some supplies that currently do not have a published maximum in the Medical Policy, such as extended wear skin barrier products and pouch deodorant. In the event that a maximum quantity is not established, it will be up to the Regional Durable Medical Equipment Medicare Administrative Contractor (DME MAC) to determine what is reasonable and necessary for the beneficiaries’ needs.

Please note: If you require both drainable and closed pouches to effectively manage your stoma, it is technically up to each Regional DME MAC to decide what is reasonable and necessary. The maximum quantity in this situation will be some combination of the two maximums listed previously. In other words, the maximum quantity will NOT be 20 drainable AND 60 closed each month. The appropriate amount of pouches should be derived by what makes sense for your situation.

If you need more than the usual maximum quantity of supplies each month, your dealer will request a letter from your doctor explaining the medical reason for your need. This type of letter may also be requested if you wish to use both drainable and closed pouches. So, it’s a good idea to make sure that your need is documented in your medical file at the physician’s office.

Recent changes in the Medicare Home Health policy may also affect the ostomy community. If you find yourself in need of home health services, the home health agency must supply your ostomy products while you are in the “episode of care.” Medicare previously allowed agencies approximately \$14–\$15 for all supplies required during a home health episode. In 2008, the amount allowed will be at least \$230 per episode with additional funding for other supplies depending upon the severity of the situation. This will help to ensure that the home health agency has the funds to appropriately supply the products you require.