

A Quarterly Newsletter for People with Ostomies

Funny, poignant book finds humor in colostomy, cancer

hen Brenda Elsagher was recovering from the permanent colostomy and total hysterectomy a colostomy ("Having a colostomy that cancer of the rectum necessitated five years ago, she realized two things: she wanted to do stand-up comedy and she wanted to go to college.

She did both – and then some.

By the end of her second class at Metropolitan State University in St. Paul, MN, Elsagher was half finished with her first book, If the Battle is Over, Why Am I Still in Uniform? Humor as a Survival Tactic to Combat Cancer. Now, with a great deal of support from Hollister, the book has had its second printing.

> Starting in this issue, **Brenda Elsagher** answers your ostomy questions. See "Ask Brenda," page 5.

"They said to write about what you know," says the 47-year-old hairstylist and business owner from Burnsville, MN. "It turned out to be something that more people needed than I ever would have thought."

The book combines Elsagher's decidedly different slant on life with isn't so bad, but I can't find shoes to match my bag.") with a serious look at how she used humor to get through times that weren't amusing.

"I enjoyed writing the book, but I did it for my kids," she says. "Now my thrust is hospitals, clinics, cancer survivor groups and ostomy groups, because these are the people who need humor."

Hollister sponsored the second printing, and donates 10 books whenever Elsagher speaks to local hospitals, cancer or ostomy groups. In addition, she has returned a portion of the book's proceeds to churches, women's groups and other organizations that use it for fundraising purposes.

Elsagher's venture as a comedian also was more successful than she anticipated. She recently produced a comedy show that attracted an audience of 375 and raised \$4,000 for the local chapter of the United Ostomy Association.

"My intention was just to do stand-up once, but I won the Twin Cities Funniest Person Contest," she says. "Some reporters learned I was still dealing with the effects of cancer,



Author Brenda Elsagher

so I made a good story. Really, though, the comedy was a springboard for inspirational speaking. I'm a funny speaker with a poignant message."

If the Battle is Over, Why Am I Still in Uniform is available at national bookstores and online through Amazon.com, www.uoa.org or Elsagher's Web site at www.brendabringsjoy.com.

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REPORT from verseas Hollister in Australia

T ollister has been distributing ostomy products in Australia for more than 20 years, even though

the continent's vast geography sometimes makes that a challenge. "The Ostomy Association (Australian Council of Stoma Organizations) is also the product distribution channel." says Annette Kirne, Sales and Marketing Manager for Hollister in Melbourne, Australia. "But a lot of people have their appliances mailed to them,

that is far away." Hollister works closely with the 22 Ostomy Association chapters in Australia, as well as with stomal therapy nurses and people with ostomies, to provide the best possible services and products to improve quality of life.

because they can't get to a chapter

The Hollister head office in Melbourne, Liberty Medical Pty. Ltd., supports 10 territory managers, located in each of the states. The headquarters office, which includes a customer service staff, fields about 40 calls a day from people with ostomies and nurses who have questions or need information on Hollister products. One staff member is a stoma therapy nurse, and most of the sales force have medical backgrounds.

"We speak at ostomy association meetings, and have our products and services displayed on permanent display boards at each association site," says Kirne. "We also attend trade display days, where we talk with people with ostomies, and we advertise in the Ostomy Journal Australia, which is mailed to people with ostomies at their homes."

In addition, Hollister's Australia office produces patient education booklets and videos that help people with new ostomies and their families understand what an ostomy is and how to live a full and comfortable life with it.



Annette Kirne

"Most people have initial concerns about having to wear an ostomy appliance," Kirne says. "This helps allay those concerns."

There are an estimated 28,000 people with ostomies in Australia a number Kirne says remains fairly constant, although there is a trend toward more temporary ileostomies.

Regardless of whether an ostomy is temporary or permanent, Hollister is ready to help people find the products that work best for them - and to be sure those products reach them, wherever they are.

OAB is nation's largest ostomy support group

In 1952, nine women in Cambridge, that would help people adjust to life MA, started meeting to discuss how to live with their ostomies. Today that group numbers more than "And we really are still very people-500 and has become the Ostomy Association of Boston (OAB) – the largest and one of the oldest chapters of the United Ostomy Association in our mission and goals have staved the country.

"The mission when the chapter was founded was to provide encouragement, support and information

after ostomy surgery," says Beth Meltzer-Abelow, OAB President. centered. For many, this is life-saving surgery, but it can also be life-altering. We know what it's like; that's why the same."

Ten OAB satellite groups, some of which are organized around specific populations such as gays and

lesbians or people with continent ostomies, meet in Boston and its suburbs. The sessions may be devoted to peer support and featured speakers who discuss health topics, including presentations by Hollister representatives.

"Hollister has been reaching out to us," says Meltzer-Abelow. "We appreciate the concern and their willingness to listen to the ostomy community."



Adapt Lubricating Deodorant

D eople with colostomies and ileostomies are always interested in better ways to control odor and speed the process of emptying their pouches.

In the past, they've used "home remedies" such as vegetable oil to lubricate pouches. Unfortunately, such approaches often lead to degradation of the pouch material, which in turn raises concerns about security and pouch integrity.

With those concerns in mind, Hollister developed Adapt Lubricating Deodorant – the first product that effectively eliminates odor and lubricates the pouch interior all at the same time.

Available in 8-ounce bottles for home use and in single-use packets for when people are on the go, Adapt Lubricating Deodorant was

developed specifically for use with ostomy pouches. Its formula (patent pending) won't compromise the pouch or seal integrity and the clear color eliminates the potential for staining.

In addition, Adapt Lubricating Deodorant is easy to use: simply add aproximately one teaspoon (5mL) to the pouch, then rub to coat the inside of the pouch. Adapt Lubricating Deodorant is not a perfume; it neutralizes odor and eases emptying by preventing pouch static and sticking.

Specially designed spouts make Adapt Lubricating Deodorant easy to use anywhere without a mess and even easier to leave the vegetable oil at home.







Adapt Lubricating Deodorant is part of the complete line of Hollister products, including **Premier** One-Piece Pouching Systems and the New Image Two-Piece Pouchings Systems with Lock 'n Roll closure, which include integrated filters for additional security and confidence.

UOA Officers Visit Hollister

When United Ostomy Association executives were in the Chicago area this spring for the organization's annual strategic planning meeting , which Hollister has sponsored for more than five years,, they stopped at Hollister headquarters in Libertyville, IL, to discuss partnership opportunities.

Those at the meeting included, from left, Ed Veome. Hollister Director of Marketing: Dean Arnold. UOA Vice President and President Elect: Mark Kennedy, Hollister Product Manager-Ostomy; Al Herbert, Hollister President; Nancy Italia, UOA Executive Director; and George Salamy, UOA Treasurer.



IAN SETTLEMIRE UOA communications director takes spin in New York

W hen Nancy Italia, executive director of the United Ostomy Association, was asked to help promote the "Get Your Guts in Gear" bike ride through New York state, she knew just where to turn.

"I was just the natural fit," says Ian Settlemire. Director of Communication Services for the Irvine, CA-based UOA. "I'm a competitive cyclist and the UOA is a beneficiary."

Settlemire wasn't daunted by the prospect of riding 210 miles in three days to raise money for three worthwhile recipients: UOA, the Crohn's & Colitis Foundation of America and the IBD Quilt Project, Inc.

Nor was he put off by the minimum \$1,800 pledge required of riders.

"My goal was \$5,000," he says. "I surpassed my goal, thanks in part to

a donation from Hollister."

Together, the 27 cyclists in the June ride raised about \$87,000. The total was more impressive, because this was the first time the event was held. The ride director, Judy Pacitti of Brooklyn, NY, rode the route from Manhattan to Saratoga Springs by herself a year ago and then decided to make "Get Your Guts in Gear" an annual event to help raise awareness of inflammatory bowel disease (IBD).

"IBD isn't well-known or talked about," Settlemire says. "The idea is to raise awareness to the level of breast cancer or AIDS, and to encourage and support additional research to benefit those who have IBD."

Settlemire helped raise awareness of the bike ride by promoting it to

"We match trained visitors/



all UOA members and launching a fund-raising campaign with ostomy supply manufacturers and retailers.

"I'm not an ostomate, but I was there to represent the ostomy community," he says. "I was also encouraging people with ostomies to participate in the ride, because it's for riders of all levels from novice to experienced. It isn't a race; it's a ride through some beautiful country."

Organizers expect "Get Your Guts in Gear" to grow as it becomes more publicized.

"I was proud to represent UOA and participate," says Settlemire. "I look forward to seeing it grow in coming years."

OAB Continued from page 2

The OAB does a significant amount of reaching out, as well, with support from Hollister for advertising and updating an ostomy resource guide for the greater Boston area.

Meltzer-Abelow credits outreach efforts such as the group's Web site (www.bostonoab.org), bulletins and ongoing communication with visiting nurses as part of the reason for recent membership increases, but says the visitor program is the heart of the OAB.

members as closely as possible with people who are about to have or have just had ostomy surgery," she says. "We try to get people together who are the same age and marital status, live in the same general area and have other common experiences. That allows us to offer one-on-one support, so hesitant people feel comfortable asking questions."

The chapter is working to expand its visitor program, as well as to establish groups for teens, young adults and people over 30.

Another long-term concern, which has yet to be addressed, is the need for materials and services for the Spanish-speaking community.

"If it weren't for our organization, so many people would be isolated and attempting to deal with their ostomies alone," says Meltzer-Abelow. "We really offer hope and support for people, and bring them the knowledge that they can have full lives with ostomies."

To become a member of OAB. visit www.bostonoab.org/info.html or call 1-800-952-9664, ext. 4656.

ODOR—Oh Dear!

Dear Brenda: Do you have any suggestions for odor problems due to my ostomy?

Tn the eight years I have been an I ostomate, I've tried many ways to deal with odor. First, let me tell you what **not** to do.

Months after my surgery, my husband and I were fortunate to get away for five days - my first trip with a colostomy. We were on a cruise ship and I noticed my pouch had begun to puff out a little. I felt proud I had graduated to my new two-piece pouching system. Cleverly and discreetly under the table, I was able to open it up and release the air. It worked great, no one noticed

and I felt comfortable and proud of my accomplishment. Hours later, I noticed a bulge, so I proceeded once again. This time, a rather foul smell permeated the air and people around me started looking around and making comments. "Do you think they just threw garbage overboard? Are we sitting near the bilge? Let's move to another location." If I'd kept that up, my husband and I would have had an entire floor to ourselves.

rose garden.

To take care of odor problems, I have used charcoal tablets, sprayed

Someone You Should Know at Hollister SABI BAIG make it even better for them than it has been."

C atisfaction is very important to Sabi Baig.

As the manager of Hollister's customer service for consumers, she is constantly looking for ways to improve.

"We are here to give the end user of Hollister's ostomy products the best possible service," she says. "When we reach one goal, we always set another. If you're in this business, you're here to make life better for people. You have to continually ask yourself how you can

As manager of the customer service team, Sabi oversees the telephone representatives who respond to consumer questions. She understands what those representatives need to know, because she used to be one of them.

Sabi started with Hollister seven years ago as a temporary employee. She progressed to a customer service representative, supervisor and now, manager. Before joining Hollister, she worked in the office of the comptroller at the College of Lake County in the northern Chicago



Another thing **not** to do: Don't think you are being clever releasing the flatulence from your pouch in a hotel elevator when it appears you are safely alone with your partner. It might take only a second to release, but the effects linger long after the innocent bystanders have entered. They know it's you. The moral of these stories: Particularly if you have a colostomy, if there are any remnants of stool left in your pouch when you release gas, chances are it won't smell like a

things in my ostomy pouch and lit matches in the bathroom. I think one of the best products is the Hollister **m9** odor eliminator spray. My family wouldn't share a hotel room with me if I didn't pack it in my luggage.

Since I do the irrigation procedure these days, I rarely have that problem. The Hollister pouch I use has a built-in charcoal filter that does wonders. The gas releases quietly and automatically, and no one ever knows. If the filter gets wet, it may lose its ability to work, but that is rare.

Once in a while, we still have an odor problem in the family. I used to always be the first suspect, but now we usually blame Dad. When it's not him, my teen-age son usually confesses proudly. If he's not the guilty one, we turn to my preteen daughter, who never admits to anything. But now we have a new puppy, so she gets all the credit these days.

Do you have a question for Brenda? Send your questions to Dear Brenda, ostomate to ostomate, at BMElsagher@aol.com



Sabi Baig makes customer satiisfaction her No. 1 goal.

suburb of Grayslake, IL. For nine years, she was a front-line customer

The United Ostomy Association: Why Join?

By Nancy Italia, Executive Director, UOA

1 7 hy join UOA?? I love that question, because it is so easy to answer!

For 42 years UOA has been a volunteer-based health organization that provides education, information, support and advocacy for people who have had or will have intestinal or urinary diversions.

UOA has more than 23,000 members across the country, many of whom belong to local chapters that meet monthly, publish newsletters, visit new ostomy patients and provide emotional support pre- and post-surgery.

The UOA publishes **Ostomy** Quarterly magazine – a 72-page, full-color magazine with medical information, personal stories, national advertisers and much more. The OQ is one of our most highly regarded services, and the only one of its type.

Seven popular **Patient Care** Guides are available to members at discounted prices and include the different ostomy types, continent

diversions, diet and nutrition, and intimacy and sexuality.

UOA members receive discounts on national events such as the Annual Conference, Young Adult **Conference** and the summer **Youth Rally** for kids ages 11 to 17.

Members benefit from our ostomate advocacy efforts, which keep ostomy supplies affordable and reimbursable by Medicare, Medicaid and insurance companies.

UOA members may join special interest groups, or **networks**, at no additional charge. Networks include parents, teens, young adults, thirtyplus, continent diversions and gay and lesbian.

Our Traveler ID Card is a helpful membership benefit to explain the need for discreet security screening at the airport, etc.

UOA's award-winning Web site, www.uoa.org, is the most complete resource available for ostomy information and online connection to other ostomates. More than 35,000 people visit our site monthly, and

sections designated "Members Only" include hundreds of articles about every aspect of ostomy and related surgeries.

It's the **best \$25 you will ever** spend. Membership covers the cost of all of this and more, and your annual dues assure that our services will be there for about 75,000 new ostomates each year.

When you join the UOA, it's like joining a family. There are thousands of ostomates across the states who are willing to share experiences, suggest solutions and serve as lifelong friends. You will discover you are not alone and as you are supported and educated by UOA members, you will be able to offer your support and personal example to others in need.

See? I told you it was easy to understand why you should join today! To join, request an application below, or go to www.uoa.org and click on Join UOA.

Clinical **Dealing with Odor** Education Corner

Tf you have a colostomy or ileostomy, Lyou may be concerned about odor. Gas and odor are created as a part of the digestive process, as well as when we eat and talk. Much of the gas in our system is a result of swallowing air, which usually occurs without our awareness. The good news is that with Hollister ostomy pouches, the odor is discreetly contained within the ostomy pouch until you empty it. Hollister pouches are made with a unique four-layer plastic film that doesn't allow odor to come through. If you detect odor when you are wearing your pouch, check for leakage of the skin barrier (the part of the pouch that adheres to your skin) and be sure the bottom of the drainable pouch is clean and closed.

There are some ways to reduce gas and odor. Try eating fewer odorand gas-producing foods such as beans and legumes, garlic, onions and milk products. Remember, however, these foods may be important to a well-balanced diet. Some com-

mon remedies for odor include eating raw parsley and taking over-the-counter medications made to reduce

odor. These don't work for everyone, however. Check with your healthcare provider or pharmacist before taking any medication to be sure it is safe for you to try. Products designed to be used in your pouch are easy and effective in preventing odor when you empty or change your pouch. Using Adapt Lubricating Deodorant or m9 odor eliminator drops in your pouch eliminates odor without the need for odor-reducing pills. If you have a urostomy (an ileal

conduit, for example), you may notice that your urine is more odorous at certain times – possibly because of something you ate or because you are dehydrated. Foods such as asparagus, boiled eggs, fish and onions are known to produce odor in the urine. These foods are not harmful to your body but you may choose to limit them if odor is

United Ostomy Association

Please send me a membership Name		
Address		
City	State ZIP	
Phone	E-mail	
Mail to: UOA, 19772 MacArthur Blvd., Suite 200, Irvine, CA 92677		

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.

Sabi Baig Continued from page 5

service supervisor in a retail business in the Chicago area.

She also was a lead customer service representative for a major pharmaceutical company in the Chicagoland area.

She understands the importance of good customer service.

"You need to make sure you meet the customers' needs and exceed your own expectations that is gratification in itself," she says.

While Sabi does have direct contact with consumers, she enjoys helping representatives with questions they can't answer. She takes a great deal of pleasure in developing and mentoring new employees and working closely with her team. "I'm here to assist in any way I can," she says. "My daily work is sur rounded by what I can do for my associates so that we excel as a team." Sabi is a native of India who immigrated to the United States 27 years ago, when she got married.



Hollister's team of experienced ostomy (WOC) clinicians — all of whom are registered nurses - includes, from left, Joy Boarini, Lynn Sacramento, Heather Budorick and Ginger Salvadalena.

a concern. Dehydration can produce dark-colored, concentrated urine that has a strong odor. Prevent dehydration by drinking water and other fluids before you exercise and periodically throughout the day.

If you use a bedside drainage collector at night, or a leg bag during the day, be sure to clean it every day. Drain the urine and rinse the system with water. You may want to try m9 Cleaner/Decrystallizer, which is designed to clear crystals and odor from bedside drainage collectors and leg bags. The m9 Cleaner/Decrystallizer comes with a convenient rinse bottle, so you can easily put the cleaning solution into the tubing. Other cleaning solutions such as bleach or vinegar are not recommended, because they can harm the vinvl material used to make the bedside drainage collectors and leg bags, shortening the life of the products and allowing odor to persist.

She and her husband, who both are U.S. citizens now, spend as much time as possible with their 21-yearold daughter and 16-year-old son.

"I love what I do and the people I work with definitely make the difference," she says. "The environment at Hollister and the service that is given to the consumers really speaks for itself. At the end of the day, you know you have served the customer to the best of your ability."

Still, to Sabi there's always room for improvement.



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 the purpose of a filter in a pouch?

A filter helps relieve gas that builds up in the pouch. When the gas escapes, the pouch has a lower profile and is more discreet.

If the gas escapes through the filter, doesn't that cause an odor?

Filters have a charcoal layer that absorbs the odor so it does not smell.

Can't I just poke a hole in my pouch?

A If you do, there will be a constant odor, since there is no charcoal layer, and a high probability that pouch contents will also leak through the hole. This can cause additional odor and embarrassment.

I wear a two-piece pouch. Can't I just "burp" the pouch when I have gas?

This usually requires you to go to the restroom, which is not always possible or convenient. Unless you are using an odor eliminator like m9 odor eliminator drops or Adapt Lubricating Deodorant in your pouch, there will be an odor when the pouch is "burped."

Sometimes it seems like it takes a long time for the gas to go through the filter. Shouldn't the pouch deflate faster?

A If gas goes through the filter too quickly, it does not stay in contact with the charcoal layer long enough to be deodorized. It is important that the gas escapes slowly so that the charcoal can eliminate the odor. If I have an odor while wearing my pouch, would a filter help?

No. Odor when you are wearing a pouch is different. The pouch film should prevent any odor from escaping.

Should everyone use a pouch with a filter?

A No. People with urostomies do not need a filter. Also, not everyone with an ileostomy or colostomy is troubled by gas, so a filter would not be necessary.

Can I swim and shower if my pouch has a filter?

If the filter becomes wet, it will no longer be effective. Therefore, drainable pouches with filters include small pieces of tape in the box to cover the filter during water activities. Closed pouches are usually changed at least once a day, so they sometimes do not have filter covers.

Are all filters the same?

Since a closed pouch is usually changed at least once a day, filters in closed pouches are not designed to last as long. Drainable pouches are usually worn for several days. Filters in drainable pouches have a protective covering on the inside so that the charcoal does not get wet from contact with the pouch contents.

Do pouches with filters last as long as those without filters?

A The wear time of a pouching system is most closely tied to the performance of the skin barrier. However, filters do have limited life spans. They can only hold so many odors. If using a drainable pouch with filter, you would expect to change your pouch every two to three days <u>before</u> the filter is inactivated.

Resources

United Ostomy Association (UOA)

19772 MacArthur Blvd. Suite 200 Irvine, CA 92612-2405 1-800-826-0826 www.uoa.org

Wound, Ostomy, and Continence Nurses Society (WOCN)

4700 West Lake Ave. Glenview, IL 60025 1-888-224-9626 www.wocn.org

Crohn's & Colitis Foundation of America, Inc. (CCFA) National Headquarters 386 Park Avenue South New York, NY 10016-8804

1-800-343-3637 or 212-685-3440 for NY www.ccfa.org

Hollister Customer Care 1-800-323-4060



Call to subscribe to the Secure Start newsletter 1-800-323-4060

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