January 2005 Volume 7 Issue 1

UOA Jacksonville Chapter #211

The Mailbag

Meetings are held at the Baptist Medical Center
8th Floor - Meeting Room C - 3rd Sunday of each month 3PM

Brenda Holloway --
President 282-8181
Ronald Perry --
Vice President 774-4082
Patti Langenbach --
Secretary 396-7827
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(800)741-0110 or
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Inside this issue

Please plan to join us Sunday Jan. 16th starting at 3 p.m.

2005 UOA National Conference
August 3-6 Anaheim, CA
www.uoa.org

A MESSAGE FROM THE PRESIDENT

I would like to thank those who attended the December meeting. We had a great turn out at Longhorn's. Attendance was 16. We hope that everyone had a Merry Christmas and a Happy New Year.

I would also like to thank everyone for his or her genius giving for our Ronald McDonald toy donations.

Our January meeting will be held on January 16, 2005 at 3p.m. at Baptist Medical Center, 8th Floor, Function room C. Brenda is in the process of trying to obtain speakers for 2005. January meeting we will probably just have a group session for anyone who needs advise or help.

Thank you,

Brenda L. Holloway, Vice President
Eugene Summerville, President

Treasurer report: $1,231.62
Patricia Langenbach, Treasurer

Newsletter is starting a new feature.
We are soliciting contributors to......**MY STORY**.
We welcome any Ostomates who would like to contribute an article telling their story. We feel this would be an inspiration to others. Please email those to Patti patti@ostomymcp.com

Register Online
http://www.uoa.org/events_yan.htm

2005 UOA Young Adult Conference
August 3-6 • Anaheim, CA

Finding Reliable Information on the Web

The Internet has become one of the best ways to research medical conditions. More than 98 million Americans regularly do just that—twice as many as two years ago, according to a recent survey. But two fundamental problems confront Web Surfers. Where do you find the best information? And who is trustworthy?

Although some Web sites dispense sound medical advice, many spread misinformation—some of it potentially dangerous. Luckily, you can maximize your chance of locating the facts you need, while minimizing the risk of getting bad information. Here's what I suggest:

Look for sites run by reputable organizations and federal agencies. Typically, experts review the articles for accuracy and the sites list the dates on which the articles were posted or updated.

As a starting point for general medical research, try the federally sponsored site, Health Finder, **www.healthfinder.gov**, which links to dozens of other government agency sites.

CBS Healthwatch, **www.cbs.healthwatch.com**, is an excellent commercial health site. For specific medical topics, try these:

- **Alzheimer's:** Alzheimer's Association—**www.alz.org**
- **Arthritis:** Arthritis Foundation—**www.arthritis.org**
- **Cancer:** University of Pennsylvania Oncolink—**www.oncolink.com**
- **Diabetes:** American Diabetes Association—**www.diabetes.org**
- **Heart Disease:** American Heart Assoc. **www.americanheart.org**

Alternative Medicine:
National Center for Complementary and Alternative Medicine—**http://nccam.nih.gov**

Learn how to perform medical searches. To answer specific medical questions, consider using a search engine, such as Yahoo (**www.yahoo.com)**, Google (**www.google.com**), or Alta-Vista (**www.altavista.com**).

There are also search engines, including Achoo (**www.achoo.com**), and Health A-to-Z (**www.healthatoz.com),** which are specifically designed for people seeking health information. To search the top medical journals, use MEDLINE (**www.nlm.nih.gov**).

Critically evaluate any Web site you visit. Ask yourself: Who's running this site? What's their motivation in providing the information? Are they trying to sell something? Do their claims sound too good to be true?

Don't be overly influenced by a Web page's appearance. A questionable site may have slick graphics while a reliable site may be "plain-jane."

Guard your privacy. Any personal data you volunteer could be sold to marketers, compiled in databases or intercepted and traced back to you. Since details about your health could affect your job or your ability to get insurance, it's a good idea to provide as little information as possible.

AN ILEOSTOMATE'S STORY

My ileostomy surgery was almost 2 years ago at the age of 65. Although thru the years I had been diagnosed with IBS and diverticulosis, neither caused enough difficulty to require consideration of diversionary surgery. In fact; it was never a consideration. However during my stay in hospital after lumbar surgery, I contacted a CDF Bacterial infection; which was not discovered until 3 days after I was home.

At that time I was brought to the Emergency Dept of the hospital where it was determined that I had this infection, which by then had destroyed my large intestine (i.e.,colon). As a result, I required an immediate irreversible ileostomy, which I declined. After my refusal, the Dr.s gave me a 24 hour regime of antibiotics, which did not help. At that point, I had 2 choices; immediate surgery or death. I chose LIFE.

Although all of my family and especially my husband were very supportive, I was extremely depressed. My husband learned to empty my pouch and assisted the nurses (both in the hospital and at home) for the first few weeks after the surgery. I finally decided that emptying the pouch had to be easier for me to do myself in the bathroom, rather than laying in bed with someone else doing it. So, with the help of the Visiting ET Nurses, I learned to empty my pouch and change my wafers.

My daughter, who was visiting after I came home from the hospital, contacted the American Cancer Society, which at the time was the only potential candidate we could think of for a support group. They gave her information and a telephone number for our Ostomy Chapter, which we called.

At this time, I must point out that the only Ostomy Nurse at the hospital I was in was on maternity leave and the person taking her place had very little information, other than to give me a kit to take home and some pamphlets. My surgeon, whom I think is wonderful did not supply me with any support information, either then or in later visits to his office. Most of the nurses in the hospital had no specialized information on ostomies, with the exception of one midnight nurse whom I only saw one time. She gave me a hint, which I use to this day.

I located some books, got a couple of catalogs from ostomate suppliers, which my daughter had ordered and called every manufacturer for free samples to try out different types of supplies. During this education process and trial and error with different suppliers, I came out of my depression and was thankful for the gift of life.

Of particular note, it was my experience that without exception, the manufacturers of the different ostomy supplies have caring and knowledgeable personnel (most are ET Nurses), who take the time to really listen and to walk you thru (step-by-step, if necessary) how to use the different supplies. As far as the distributors I was in contact with, there is one person at one company who helped me immensely and was always available to listen to my concerns and/or problems. She helped me many times. That is Patti Langenbach at Medical Care Products in Jacksonville, tel# 800-741-0110. If this is a free advertising plug, she more than deserves it.

I was also fortunate to meet a woman who had been an ostomate for a few years prior to my surgery at the Ostomy Meetings. She lives in my town, we have since become friends and I have received numerous helpful hints from her.

(Continued on page 4)

Although I experimented with many types of supplies, I finally settled on Convatec, which I am very happy with. Since my stoma is an irregular shape, I was using the cut-to-fit wafers, but since it is only 5/8" deep, I periodically had some difficulties with leakage. This most likely was because I tried to get the wafer too close to the stoma to avoid exposing the skin around it to the effluent. I have recently tried the Convatec convex wafer, which is not cut, but shaped manually, with great success.

I live a full and rewarding life, with very few limitations and unless I choose to advise people of my ostomy, no one would know of it. Let me tell you a few of the hints for successful managing of my ileostomy:

I use Scope mouthwash in the water that I flush my pouch with. It helps to reduce odor.

Ost-O-Fresh is a clear liquid deoderant (6 to 12 drops in pouch, after rinsing), which I find very effective. I understand Medicare will be restricting the number of bottles per month to 2 in the near future. Ask your surgeon for a script calling for more to send to your supplier to obtain coverage, should you choose to use a deoderant. I use approximately 6 bottles per month.

Paper towels – Cut in quarters. Excellent for use when changing wafers, rather than washrags.

Lined waste paper basket right under the stoma when changing in the event it activates while changing. This activity happens frequently if one is an ileostomate. My bathroom sink is not near the toilet, thus I use a bench to sit on which is next to the sink, when changing my wafer.

Best time to change the wafer is first thing in the morning, without eating or drinking anything. Generally, there is less peristatsis that way. Although I found if I eat chocolate the night before, all bets are off.

Never leave home without a small rinse bottle. Also, if you will not be near home, always take a change, should a leak occur, where you wouldn't be able to get home in a reasonable time.

If in a hurry and especially if the effluent is very liquidy, a rinse is not always necessary. Just empty and thoroughly wipe the end of the pouch with toilet paper.

Cuff your pouch when emptying, to make it easier to rinse and clean.

Chew, chew, chew --- Always a fast eater before my surgery, I had to retrain myself and consciously chew my food very thoroughly. Initially, the recommendations were to avoid nuts. I found I can eat nuts; but one at a time and very thoroughly. Interestingly enough, one really gets to enjoy the flavor of foods much more when thoroughly chewing. One blockage will help you to remember to chew your food. That happened to me with steak and the pain started within half an hour after I ate.

If you do get a blockage, rub your stomach gently and use a heating pad on it for about ½ hour. If that doesn't work, try a warm bath for 20 to 30 minutes. If you are still blocked at that point in time, call your Dr. and go to the hospital. I was fortunte in that my blockage began to clear after the hot bath. The abdominal pain is intense until it does clear.

Support your local Ostomy group by attending the meetings. You may be surprised at the helpful hints you find out and the potential to meet to meet other people who are "walking in your shoes". Continue to support the national organization, as it is responsible for pushing thru legislation for the medical coverage that ostomates enjoy. Their lobby is active and effective.

At this point, almost 2 years later, I'm comfortable with myself and my ostomy. I think there will always be an underlying "fear factor" of a leak. But, as I have found out, you just deal with it as it occurs, just like any other situation in life.

Grace Fleury 10/13/04

Ostomy Chat Room Weekly Meetings

Yahoo Peoples with Ostomy2* - Mondays, 8:00 pm US Central time
http://clubs.yahoo.com/clubs/peopleswithostomy2

StuartOnline Ostomy Chat* - Tuesdays, 8:00 pm US Central time
http://www.stuartonline.com/id10.html

Community Zero (Ostomy) Support* - Wednesdays, 9:00 pm US Eastern time
http://groups.yahoo.com/group/ostomatessupport/

Shaz & Jason's Chat* - Saturdays, 8:00 pm UK time / 3:00pm US Eastern Time
http://www.ostomy.fsnet.co.uk/chat.html

Yahoo UK Ostomy Support* - 1st & 3rd Sundays, 8:00 pm UK time / 3:00 pm US Eastern Time
http://clubs.yahoo.com/clubs/ukostomysupport

Use this form to join our chapter! Annual dues are **US$25.00**. If you cannot afford to pay dues at this time, you may still be accepted as a "local-only" member.* **You do not have to be an ostomate to be a member and/or support the work of UOA. All information on this form will be kept confidential.**

Name____

Address ____

City ______________________State __________Zip ______________

Phone# Home __________________ Work# ____________________

Email Address ____________________________

Type of intestinal or urinary diversion: Colostomy __ , Ileostomy __, Urostomy __, Ileoanal Pull-thru __
Continent Ileostomy __, Continent Urostomy __, None __, Other __

___ Please bill me for annual chapter dues of US$25.00

___ Dues payment enclosed - make check payable **to U.O.A. Jax Chapter #211**
___ Master Card, Visa or Discover #________________________expiration________
___ I cannot pay dues now and wish to be a local member only*

You may use my name in chapter Newsletter & Directory: Yes __ No __

Mail to: Patti Langenbach, Treasurer, UOA Jacksonville Chapter ,
PO Box 10239 Jacksonville, FL 32247-0239

United Ostomy Association , Inc
www.uoa.org

MEETINGS ARE HELD AT THE
BAPTIST MEDICAL CENTER
8TH FLOOR - MEETING ROOM C -
3RD SUNDAY OF EACH MONTH
3PM

UOA Jacksonville Chapter
PO Box 10239
Jacksonville, FL 32247-0239

Phone: (904) 396-7827
Fax: (904) 396-7829
Email: patti@ostomymcp.com

TO:

**Join us
Sunday Jan.
16th starting at
3 PM**

**Baptist Medical Center 8th
Floor
Meeting Room C**

**For information
Phone: 904 396-7827**