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 744-4082 Beth Carnes - Treasurer 786-2359 Patti Langenbach - Secretary 396-7827

> Contact: Patti Langenbach (800)741-0110 or (904)396-7827

Inside this issue

Minutes of the January	. 2
UOA 2002 Advocacy Report	.3
The Overactive Ileostomy	4
Ostomy Chat Room	
Weekly Meetings	5

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

The United Ostomy Association 41st Annual UOA Conference Las Vegas, NV August 10-13, 2003 www.uoa.org

Medical Care Products, Inc Toll Free 800 741-0110

WE ARE ON THE NET www.ostomymcp.com

<u>A MESSAGE FROM THE PRESIDENT</u> <u>& VISITATION COORDINATOR</u>

I would like to take this opportunity and thank everyone that attended our January, 2003 meeting. Louanne, the representative from Hollister was there and put on a very informative presentation about their new Ostomy supplies. We would also like to thank her for coming.

In **February 2003**, a suggestion that we breakdown into groups according to our types of ostomates and give each other helpful hints, ideas and discuss any problems that each may be facing. So we have decided to go ahead and do this. Soooo, I need your help. We need the "OLD TIMER'S" to attend, this way they can share with the new ostomates their experiences and give them helpful advise and tips. So, please try to attend this meeting and help the new ostomates and new members.

I would like to thank Eugene Sommerville for helping me on January 8, 2003 put the Doctor and ET's folders together. I had some medical problems, which keep me from distributing them last month so I am just going to say I am going to try to get this done this month.

Please mark your calendars for March 16, 2003, as Patti will be putting on a Cymed presentation, as they do not have a representative for this area at this time. Patti volunteered to put it on and Cymed will be mailing her all the information necessary to present their product so please plan to attend.

DO NOT FORGET that we have dedicated the month of April (April 27, 2003) for our Visitation Program Training so please mark your calendars. It is important for me to know if you plan on attending. Please contact me so that I have enough booklets made up for the training. My numbers are (904) 282-8181 or (904) 742-6504 (cell). We need certified visitors so please think about it, call me and plan on attending.

Thank you for your time and hope to see you at the meeting on February 16, 2003.

Sincerely, Brenda L. Holloway UOA, Jax Chapter 211 President & Visitation Coordinator

UOA Jacksonville Chapter is now on the Web http://www.ostomymcp.com/chapter/Jaxchapter1.htm

Minutes of the January 19th Chapter Meeting

The meeting was brought to order at 3:15 by president, Brenda Holloway. Brenda introduced our guest speaker, Louanne King with Hollister Inc.

Louanne King was here last January but graciously agreed to return this year. She explained that Hollister was started 80 years ago by a printer who sold birth certificates to hospitals. He later started producing ID bracelets for hospitals. After an employee's relative had a colostomy, he introduced Hollister's Karaya pouches (which are still on the market today). Hollister is now a totally employee owned company.

Louanne had several products to display including the new image two-piece line, new adapt paste and rings and M9 pouch deodorizer.

Brenda wanted to thank Betsy Raiford, RNP with Riverside Internal Medicine for the generous donation of a personal copier and fax machine for the chapter to use. Betsy is also an Enterostomal Nurse.

We also received a \$40.00 donation from Annabelle Merkel to help cover the cost of sending a newsletter to a new ostomate.

Brenda and Eugene put together over 50 packets for doctors and new patients.

Our Visitation training program will be the last Sunday in April. This will be held during our regular meeting. More information to follow.

Brenda said that the UOA website has been changed (www.uoa.org). Patti also said that there is an excellent website for ostomates (www.stuartonline.com). This website has a chat room every Tuesday at 9 pm EST.

The national conference is Aug $10^{th} - 13^{th}$ in Las Vegas. Patti said we should start raising money to help send Brenda.

Patti read the minutes from the December meeting.

Beth read the Treasurer's report. We have \$762.92 in the bank with \$20.00 petty cash.

The 50/50 for December and January was \$5.50.

Ron Perry just got out of the hospital a few days ago.

Beth recommended that we use the February meeting as an opportunity to break up into groups. Patti volunteered to speak as the Cymed representative at the March meeting and April will be the Visitation Training Program with Kathy Johnson, CETN.

The meeting was adjourned at 4:15 for refreshments and further discussion with Louanne.

Minutes respectfully submitted by Patti Langenbach, Secretary

2003 UOA YOUNG ADULT CONFERENCE

July 17-19 2003
Holiday Inn East
St. Paul, MN
http://www.uoa.org/yan/yacflyer.pdf (Adobe PDF,
95kB)
http://www.uoa.org/yan/
Contact: info@uoa.org

11th IOA World Congress

Bangkok, Thailand October 26-30, 2003

The Amari Watergate Hotel http://www.amari.com/watergate/index.htm More Information: http://www.ostomyinternational.org/congress2003.htm Contact Di Bracken IOA Vice President: ioavicepresident@ostomyinternational.org

UOA 2002 Advocacy Report by Linda Aukett, advocacy@uoa.org Chair of UOA Government Affairs Committee, transmitted by e-mail on Jan 1, 2003 to members of UOA's Action E-List

Happy New Year!

After looking over some statistics for activity on the UOA Advocacy page during the past year, it is timely to let you know what that activity was, and the result it obtained for UOA and our members. We owe a great debt of gratitude to those of you who have taken advantage of the Advocacy page to contact your elected officials on behalf of UOA.

First some raw numbers:

- 2,545 email messages were sent through the communication function of the Advocacy page. (There may have been additional ones printed and mailed -- we don't have a way to tally those unless you let us know you have done it.)
- While some of those went to media outlets and US agencies, the vast majority (2,291) went to members of Congress.
- Every US Senator received a message about at least one UOA issue (in fact, every Senator received at least two messages).
- 433, or all but 2, US Representatives received at least one message.
- Florida and Texas letter-writers lead the pack, with 121 messages to Senator Bob Graham, 112 to Senator Bill Nelson, and 86 each to Senator Phil Gramm and Senator Kay Bailey Hutchison. Other states with highly-active letter-writers include California, Illinois, Nebraska, Massachusetts and Michigan.
- Letter-writers were very responsive to our requests for letters on the major issues of 2002:
- 388 messages asked elected officials to intercede with CMS to retain the Medicare codes that were put in place as of 4/1/02;
- another 173 letters were sent to thank Members of Congress for their support that achieved those 4/1/02 codes to begin with;
- 329 messages asked for support of the "IBD Act";
- 272 messages urged officials NOT to support the concept of competitive bidding for durable medical equipment, and an additional 251 messages specifically opposed Senator Graham's bill for competitive bidding (S.3098).

Now, the outcomes:

MEDICARE CODES:

Our letters about retaining the Medicare codes had some indirect benefits in the overall campaign. Only a few Congressmen actually wrote letters to the Centers for Medicare and Medicaid Services (CMS) on the issue, but we know that phone calls and other inquiries were made to CMS, heightening their awareness that this was an area of concern. In the long run, the 4/1 codes that recognize "pouch features" such as filters have been repealed and a new code system put in place (more about that elsewhere). However, CMS DID listen to our concerns about the very low reimbursement levels that existed, and they DID agree to base fee schedules for the new system on current pricing -- this is a major concession on their part that would not have happened if it were not for the heightened awareness that your letters caused.

Another bit of evidence about this is that the CMS administrator made a comment in a Senate committee hearing about the number of letters his office received on the issue of low reimbursement rates for ostomy supplies. It was arranged that his office would receive a copy of each letter you sent to Congress on that issue.

IBD ACT:

Although this bill did not come up for a vote in the session of Congress that concluded in early December, this is not unusual for a new bill. Co-sponsorship has grown as a result of our letters, and this really improves the chances that the bill will be successful in the long run.

One feature of this particular campaign should be noted, and applauded. The issue of IBD caused you--UOA members--to ask your friends and relatives to come to the UOA Advocacy page and send a message -- even though they are not chapter or association members. We are very grateful for that.

We also hope that you will do the same for other issues in the future ... you don't have to have a stoma to educate an elected official that ostomy products should be reimbursed fairly.

COMPETITIVE BIDDING:

The entire durable medical equipment industry heaved a sigh of relief when Congress adjourned without passing a bill that would impose competitive bidding in some part of the US (except for two test areas that have been ongoing). However, there are some very strong proponents of this as a way to control Medicare costs and to find funds to pay for other desirable things such as a prescription drug plan. The campaign is not over but only taking a break.

Still, there has been some evidence that one of the strongest proponents, Florida's Senator Graham, is slightly less committed to it than he was. We think we can take at least a little credit for that, as our FL colleagues generated a very high volume of "noise" on this issue.

There is no doubt, though, that the issue will return when Congress reconvenes, and we will have to continue to educate our eelected officials that competitive bidding is inappropriate as a method for providing ostomy supplies (or other DME). We hope we can count on your continued support and activity on these and other issues as they arise. The Government Affairs

ommittee will continue to be actively engaged in a variety of advocacy-related areas, but we rely very heavily on YOU to interpret the issues to YOUR elected officials, educate them about how the issue affects YOUR life and, as one of their constituents, seek their action and assistance.

LOOKING FORWARD:

We hope you have had a chance to see the new UOA website design, and that you will bookmark the location of the Advocacy page www.uoa.org/advocacy. Visit on a regular basis and note the new look within the Advocacy page that will be introduced over the next few weeks. We will try to more clearly define news items, and (in the best New Year's Resolution tradition) put the Advocacy home page on a diet, highlighting there only the most urgent issues.

This plan emerges from a recent conference call with a technical advisor at Capitol Advantage (from whom we "rent" the communication software), who says we are doing better than many of their customers, but can still take some steps to maximize the usefulness of the page. The planned "tweaking" will make it more user-friendly for you and will help us more effectively achieve our ultimate objective of impacting on the public policy decisions that affect us.

Three things YOU can do, if you would, please:

- 1. Please inform others in your chapter that the Advocacy page exists and ask them to join the "Action E-list" as you have. See the "Pass the Word" section at the very bottom of the front page for a quick and easy way. Tell your chapter newsletter editor, your chapter's webmaster, etc.
- 2. When specific issues arise, please encourage other chapter members, family and friends to visit the site and send their own message.
- 3. Note that in future we will often ask you to fill in your own "subject" when you send a letter to your Members of Congress. It has been pointed out to us that if a Senator gets 10 or 15 letters with the same subject heading, their staff is quick to realize that some organization is orchestrating the message -- and might begin to ignore other letters with the same subject at the top. This really defeats the process, as we want additional messages to be read and to be reinforcements of our view. Our message text will still be there (and we do hope you will enhance it with some personal information) -- all we ask is that you compose your own subject field, so the messages look a bit more individual when they are received in Congressional offices.

THANK YOU AGAIN for all your help and support in 2002. We look forward to working with you in 2003 to help other UOA members and to achieve public policy decisions that will be good for people with an ostomy

The Overactive Ileostomy

from So. NV Town Karaya; via Oklahoma City (OK) Ostomy News

An overactive ileostomy can result from a variety of problems. If the small bowel is inflamed due to Crohn's disease, radiation injury, or bacterial/viral enteritis, the output will be profuse. If there is narrowing of the small bowel close to the stoma, where the ileostomy goes through the abdominal wall, a pressure backup can lead to explosive high output.

Any food that has a laxative effect should be eliminated or, at best, kept to a minimum. People with lactose intolerance will have high output if they use any kind of milk product, including powdered milk, which is found in many prepared foods. Excessive drinking of fluids will also increase the ileostomy output. An ostomate who has had a gall bladder removed may have increased output. Medicines to counteract bile salts can be used if the problem is related to gall bladder removal. Many prescriptions and OTC drugs list diarrhea as a side effect.

The ostomate should work with his physician to evaluate the problem. Once disease can be ruled out, therapeutic emphasis can be placed on diet, utilizing foods that decrease output. Bulk laxatives can be used with each meal to absorb and solidify some of the liquid output.

Check Out New UOA Website

United Ostomy Association has updated their Web site www.uoa.org. The site has been completely redone and is packed full of some great reliable information.

IOA Today "A Quarterly Ostomy Related Newsletter" Bringing You Ostomy Related Information From Around the World www.ostomyinternational.org

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/chatroom.htm
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
CityStateZip
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 UOA Jacksonville Chapter is now on the Web http://www.ostomymcp.com/chapter/Jaxchapter1.htm



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

Join us Sunday Feb 16th starting at 3 PM

Baptist Medical Center 8th Floor Meeting Room C

For information Phone: 904 396-7827

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