

**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

**A MESSAGE FROM THE PRESIDENT  
AND VISITATION COORDINATOR**

I would like to thank everyone for attending our May meeting. We broke down into groups to a discussion each different ostomy. Well, it ended up all of us getting together and telling about our experiences.

Eugene Sommerville reported that he had attended the Crohn's Colitis support group on a Wednesday in May, 2003 at 7:30 p.m. at the Jacksonville Library, the Southeast Branch off JTB and Gate Parkway. The next dates for this support group are on Monday, June 2, 2003 and Monday, August 4, 2003. Anyone can attend if they wish.

Please keep in mind the 41<sup>st</sup> Annual United Ostomy National Conference in Las Vegas from August 10–13, 2003. We plan on sending someone to this conference this year and monies are need to this. If you would like to donate toward this cause please contact me at (904) 282-8181. Thank you.

We have had no new visitation contact but this may be due to the surgeon and the malpractice issue.

Thank you for your time and hope you attend the meeting on June 22, 2003. I will be unable to attend this meeting as I have prior obligations with my church. Therefore, Patti from Medical Care Products and our secretary will be hosting this meeting since Ron has been ill.

**REMEMBER THIS IS THE 4<sup>TH</sup> SUNDAY DUE TO FATHER'S DAY.**

Sincerely,  
Brenda L. Holloway, President  
UOA, Jax Chapter 211



**Medical Care Products, Inc**  
Toll Free 800 741-0110  
We are on the Net  
www.ostomymcp.com

**Please plan to join us  
Sunday June 22nd  
starting at 3 p.m.**

**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](mailto:info@uoa.org)

## **Ileostomy Do's and Don'ts**

From The New Outlook, Chicago's North Suburban Chapter UOA

### **A collection of ileostomy don'ts:**

#### **Don't fast**

Fasting can lead to serious electrolyte imbalances, even when adequate fluid intake is maintained.

#### **Don't limit fluid intake**

Ileostomates are always slightly dehydrated due to the constant outflow of fluids, so maintaining fluid intake at all times is a must. You need to drink at least two quarts of fluids a day.

#### **Don't eliminate salt from your diet**

Since salt is also lost with the fluid outflow, even those with high blood pressure should not eliminate salt altogether. Be careful adding excessive salt to your diet. The normal American diet is already loaded with more than enough salt for your needs. Consult your physician for your recommended salt intake when other physical problems are a consideration.

#### **Don't put things into your stoma**

Do not allow anything to be put into your stoma without your own doctor's personal supervision. Less familiar doctors have sometimes given incorrect routine orders in hospitals for enemas, etc. Question any procedure that intrudes upon the stoma, including suppositories. Do know how to irrigate your stoma in case of a blockage.

#### **Don't take any medication unless you know it will dissolve quickly and be fully absorbed**

Before filling new prescriptions, be sure to ask your pharmacist whether it will dissolve in the stomach quickly. Coated and time-released medications will not be absorbed, and will pass through without benefit. If in doubt, purchase only six pills, and try them before getting the rest of the prescription. Women should be especially alert when taking birth control or estrogen replacement medications.

#### **Don't take any vitamin B-12 product for granted**

Have your doctor check your B-12 level whenever you have a blood test taken. Some ileostomates with some of the small intestine missing may require B-12 injections when they do not absorb enough of this vitamin.

#### **Don't give blood**

Ileostomates cannot afford to lose fluids even though they are healthy. Giving blood may lead to a serious dehydration issue.

**For more information about the  
2003 UOA Conference please visit  
the UOA Web: [www.uoa.org](http://www.uoa.org) or call  
toll free 800 826-0826**

**2003 UOA Young Adult  
Conference July 17-19, 2003  
being held at the Holiday Inn East  
St Paul MN. For more information  
visit the UOA Web: [www.uoa.org](http://www.uoa.org)  
or call toll free 800 826-0826.**

**BEHIND THE SCENES - 5/1/03: Your UOA National Team at Work.****UOA Networks.**

- As reported in the January Behind the Scenes we now have four distinct youth and young adult “networks” or national groups. Each network will have its own specific programming “Track” at the UOA Annual Conference. Also each network will have its own space on the newly designed UOA Web site and in the Ostomy Quarterly and will be given the opportunity for its own message board and chat room on the UOA Web site.
- To remind everybody, our youth networks are: The Parents Network which serves parents of children up to 17 years old with ostomies or related procedures. This year we are introducing our Parents Scholarship Program where we will be sending families to our Annual Conference in Las Vegas for the entire event. The UOA Teen Network serves the 12 – 17 year old segment and complements our annual Youth Rally. They will be introducing a “Mentoring” program where we will be matching up teens with a same sex young adult with the same procedure, like the Big Brother, Big Sister program. Our Young Adult Network focuses on the 18 –25 to 30 year old group. This year we will be conducting the first Young Adult Conference specific to this group. This conference will be July 17 – 19 in St. Paul, Minnesota. Finally we have our Thirty Plus Network for young professionals, singles, newly married ostomates, etc.
- **Strategic Partners**
- Several years ago, we concluded that without help from a number of our strategic partners, UOA would have much less ability to both deliver and market its services. The partnership program is now moving into its third year. Following a meeting at Cymed in Berkeley, CA, on May 5, we now have the following partnership meetings scheduled: May 15—AOS in Milwaukee; May 15—Hollister in Libertyville, IL; June 5—CCFA in New York City; June 6—ConvaTec in Skillman, NJ and j-pouch.org in Philadelphia, and June 17—Coloplast at the WOCN Conference in Cincinnati.

***Conferences and Events***

- We now are moving into the busiest time of the year for conferences and events. In the next three months your leadership has the following:
  - WOCN Annual Conference, June 14–17 in Cincinnati.
  - UOA Youth Rally, July 12–16 in St. Paul, MN.
  - UOA Young Adult Conference, July 17–19 in St. Paul, MN.
  - UOA Annual Conference, August 10–13 in Las Vegas.
  - UOA Canada Annual conference, August 14–17 in Saskatoon, Saskatchewan.
- The SARS epidemic has reached into our international activities. The World meeting of the International Ostomy Association scheduled for October has now been cancelled over SARS concerns

## ***Advocacy and Prevention***

- In March and April UOA members took part in two events in Washington, DC, both aimed at increasing the funds for two federal agencies:
  - The National Institutes of Health for research into diseases that lead to ostomy;
  - The Centers for Disease Control & Prevention, for activities to promote colon cancer screening.
  - Nine members attended the Public Policy Forum of the Digestive Disease National Coalition March 23-24, and 3 members attended the lobbying effort of “One Voice Against Cancer” April 7-8. Team visits were made to Congressional offices to educate Congressmen about the value of research.
- UOA continued to follow developments in California and Oregon – both states may terminate access to ostomy supplies for their residents who rely on Medicaid. A number of California members who received letters from UOA began to educate their legislators, and several attended a Budget Committee hearing on 3/24, where one member was able to testify to the fact that ostomy supplies are not optional. We have proposed ways that California may save Medi-Cal funds on ostomy supplies without cutting them completely.
- Government Affairs Committee (GAC) Chair Linda Aukett and GAC member Vince Puma presented information about United Healthcare and Florida Medicaid to a meeting of the Florida Association of ET nurses on 3/15 to alert them to progress made and build a basis for collaboration in the future.
- GAC Chair Linda Aukett and Consultant Colin Cooke, and others from the Coalition for Access to Medical Services, Equipment and Technology (CAMSET) met with General Accounting Office officials to discuss the problems inherent in competitive bidding, a mechanism that Congress seems intent on implementing in urban areas. Since then we have submitted additional background information.
- Content was perfected for a “web sticker” that chapters can add to their own website, directing their site visitors to the UOA Advocacy page to send Congressional messages.

### **Statistics:**

- The GAC chair responded to 70 calls and e-mails seeking assistance with Medicare, other reimbursement problems and other advocacy issues.
- Nine issues were added to the Advocacy page at [www.uoa.org/advocacy](http://www.uoa.org/advocacy).
- Seven Alerts were sent to the members of the “Advocacy Action E-List.”
- Three Medicare updates were sent subscribers to the Distributors e-list.
- On April 4–6, Ann Favreau was part of a panel and distributed UOA materials at the Colon Cancer Alliance Conference in Washington, D.C.

### **Check Out New UOA Website**

United Ostomy Association has updated their Web

### **UOA Jacksonville Chapter is now on the Web**

<http://www.ostomymcp.com/chapter/Jaxchapter1.htm>

**IOA Today** "A Quarterly Ostomy Related Newsletter" Bringing You Ostomy Related Information From Around the World [www.ostomyinternational.org](http://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 \_\_\_\_\_

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](http://www.uoa.org)

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

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BAPTIST MEDICAL CENTER  
8TH FLOOR - MEETING ROOM C  
3RD SUNDAY OF EACH MONTH  
3 P M

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

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

T O :

**Join us**  
**Sunday June**  
**22nd starting at**  
**3 PM**  
**Baptist Medical Center 8th**  
**Floor**  
**Meeting Room C**  
**For information**  
**Phone: 904 396-7827**

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