August 2005 Volume 7 Issue 8

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
Beth Carnes --
Treasurer 786-2359
(800) 741-0110 (904) 396-7827
patti@ostomymcp.com

Contact: Patti Langenbach
(800)741-0110 or
(904)733-8500

Inside this issue

Please plan to join us Sunday Aug. 21st starting at 3 p.m.

United Ostomy Associations of America (UOAA)

What Is UOAA?
UOAA is a national network for bowel and urinary diversion support groups in the United States. Its goal is to provide a nonprofit association that will serve to unify and strengthen its member support groups, which are organized for the benefit of people who have, or will have intestinal or urinary diversions and their caregivers.

UOAA's Mission
UOAA is an association of affiliated, nonprofit, support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.

It is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large.

It is organized to grow and develop while remaining independent and financially viable.
Membership in UOAA is open to any former UOA chapter or other nonprofit support group that chooses to affiliate with it.

UOAA will publish a quarterly magazine, The PHOENIX, that all interested individuals can subscribe to.

UOAA will obtain an IRS 501(c)(3) non-profit status that its affiliated support groups can use as an umbrella.

UOAA's Organizing Steering Committee consists of the following individuals:

Ken Aukett President
Julielyn Gibbons Vice President
Dave Rudzin Treasurer
Ginnie Kasten Secretary
Charlie Grotevant Director
Ron Titlebaum Director

Other people involved in the creation of UOAA include:

Ian Settlemire The Phoenix Publisher
Linda Aukett Advocacy Chair
Bob Baumel Webmaster

For more information please contact Ken Aukett kenaukett@uoaa.org

End of an Era
by Dean Arnold, UOA President

As you have most likely heard by now, the UOA will be closing at the end of the business day September 30, 2005. This decision comes with a heavy heart. The organization has helped thousands of people in its 43 years of education, information, support and advocacy. Many strings will be tugging at our hearts as the organization winds down.

The decision was not made in a vacuum; there have been signs of this possibility going back to 1998. At the UOA Semi-Annual Board of Directors meeting in March 2005, a task force researched options for the organization. The first and foremost issue facing UOA is lack of support for programs and services, resulting in inadequate funding.

Revenue Sources
How do we raise funds? The majority comes from dues and donations. Both of these are based on the number of dues-paying UOA members. During the last 10 years, membership has dropped from 36,800 to 21,100, reflecting a steady decline. We currently have an estimated three percent market share of potential members. Regardless of countless membership recruitment and retention programs, membership continues to drop at an average yearly rate of four percent—the reasons are many.

Medical advances have reduced the number of permanent ostomies. The latest statistics indicate that 40 percent of current surgeries are temporary. Ostomy management information that we have offered traditionally is available free from many sources including the Internet. The major manufacturers are publishing free informative newsletters and magazines, offer 24-hour “hot lines” have nurses on staff to assist with medical and product issues and assist with advocacy issues and reimbursement information.

While at one time UOA had close to 600 chapters, currently there are only 350 and more than 35 have disbanded in the past 12 months. In general, the chapters are disbanding for reasons related to age or health issues, lack of leadership, lack of new members and lack of interest by their members. We estimate that close to half of chapters do not open mail coming from UOA in a timely fashion, if at all. They are not utilizing the materials created for them to improve newsletters, programs and marketing, and they do not share news about the national organization’s services with their local members. Only 25 percent of UOA chapters vote in national elections to select the board of directors and officers. Thirty-seven percent of chapters currently have fewer than 15 members and 80 percent have fewer than 50.

In the past, new members were recruited from the UOA Visiting Program. With the passing of patient information confidentiality laws, we cannot visit in the hospital unless the patient signs a permission form for the WOC nurse to call a visitor. With shorter hospital stays, most patients are still on medication and do not understand the significance of a visitor. In addition, as the role of the ET nurse has broadened and they generally spend only 20% of their time on ostomy care, fewer and fewer of them become UOA members or donors. These are only a few of the environmental issues affecting our organization.

As for the internal factors, the level of membership is below the threshold that can support our programs and services. Our past leadership has tried to develop new sources of income without success. Industry has maintained their current support, but without additional support from fund raising, our revenue remains inadequate. Only ten percent of UOA members respond to our fund raising campaigns with a donation and only 12% of chapters donate to programs such as the Youth Rally, Parents Scholarship Program or other general fundraising efforts.

Additional issues include the rising cost of doing business in a highly technological society and operational costs such as rent, printing, postage and insurance also continue to rise. Despite the opportunity that technology provides to deliver information cheaper, faster, better, only 10% of UOA members have provided their e-mail address, making it difficult to communicate via this efficient medium. The UOA Board of Directors instructed the task force to look at the following options and make a recommendation:

Merger
The task force was challenged to determine if merging with another organization was feasible. We had dialogue with one, but it proved unattainable because our missions were not aligned.

Downsizing
We determined that all the significant, direct membership benefits could not be done for much less than what we currently spend. Even with a substantial dues increase that we knew would not be well received, we could not raise the funds needed to support the programs and services most used by the membership. (In 1995, a $2 dues increase resulted in a 17% decrease in membership.)

Association Management Company
We spoke with an association management firm, as well as another organization that uses an association management firm to run their organization, regarding the

cost of outsourcing programs and operations. The estimated costs of such an option would only save our organization less than 10 percent of our costs and could affect program quality and customer service.

"Virtual" Organization
The task force explored a UOA virtual organization and determined this concept would require state-of-theart technology and several new electronic services. It could not be supported by a volunteer-dependent organization like ours and the costs are prohibitive. In addition, a large percentage of ostomy patients do not have access to the Internet and would not be served by technology.

Dissolution
In the end, we had to accept that we met the goal of the organization to help those who have or will have ostomy surgery, to the best of our ability. We can proudly state that $.88 of every dollar we spend goes directly to that goal today. Our organization was founded in 1962 to disseminate information to all who joined. Support for individuals having ostomy surgery was nonexistent at the time our group was founded. Supplies were less than adequate (if any) and came with no support. Today the support umbrella is as close as the Internet. Supplies are modern and support by the manufacturers is a priority for them. People get the information they need and move on. Society has changed to a culture of "non-joiners"; our organization is based on joiners (members).

What Does This Mean for UOA Chapters?
UOA will do all it can before September 30 to assist chapter transition to independent support groups. Regional Coordinators from the Field Service Department will be sending a letter to chapter presidents in late June. Additional materials will be sent to chapter leaders, along with a final list of members and expiration dates, later this summer to inform them how to apply for their own tax-exempt status, change their name if necessary, revise newsletters, etc. Special sessions for chapter leaders will be held at the conference in August and additional information will be sent via *The Insider* newsletter and the last *Ostomy Quarterly* magazine. It
is expected that these independent support groups will continue their good work in the community to serve new ostomates and their caregivers.

We can proudly claim victory and accept that we have changed the world for past, present and future ostomates. To all of those who contributed their time, talent and treasure to the UOA over the past 43 years, I want to THANK YOU for all you did from the bottom of my heart.

Dean Arnold
UOA President
president@uoa.org

Ostomy Quarterly to End

The Ostomy Quarterly magazine (OQ) has been published continuously by the United Ostomy Association (UOA) since December, 1963 and is the only nationwide periodical specifically addressed to ostomates - people with ostomies.

The Fall 2005 issue will be the last issue of the Ostomy Quarterly. Two-issue subscriptions (Summer and Fall) are available for U.S. residents only for $15.

CRANBERRIES - FOR AND AGAINST FOR UROSTOMATES
Via: Snohomish county, WA & S. Brevard FL Newsletter

FOR– The secret ingredient in cranberries that is pivotal in preventing urinary tract infections (UTIs) is concentrated tannins in the juice, called proanthrocyanidins. In a Boston study published in the Journal of the AMA, cranberry juice was found to be effective in reducing the incidence of UTIs and the need for antibiotic treatments. This has important implications for persons with ostomies and continent diversions. Recurrent UTIs can be common in persons who catheterize frequently. These can be more evident if proper hand washing and cleaning of catheters is not done routinely. In addition, a large proportion of women over age 65 will experience at least one UTI per year. How does this special ingredient in cranberry juice work? The tannins from cranberries simply prevent E-coli bacteria, the main culprit in urinary infections, from adhering to cells that line the walls of the bladder and kidneys. The bacteria thus will "wash out" before infection can develop. Scientists in the Boston study believe that the routine addition of cranberry juice to dietary regimes in circumstances where UTIs have a high incidence, would be sensible. AGAINST—An article from the Mayo Clinic says drinking cranberry juice to prevent recurring bladder or urinary infections is an "old folk" remedy. Does it work? Maybe—but don't count on it. A key to preventing a bladder infection is blocking the growth of the bacteria that cause the infection. Researchers have two theories about how cranberry juice makes urine more acidic, discouraging the growth of bacteria. But scientists don't know whether a realistic amount of cranberry juice can produce enough change in urine acidity to affect bacteria. The second theory is that cranberry juice keeps bacteria from "sticking" to the bladder wall where they multiply and cause infections. This theory was confirmed in the laboratory and in mice, but results vary in humans. We do know that taking 500mg of vitamin C (ascorbic acid) twice a day along with cranberry juice can cause acidity of urine. Still, if you think you have a bladder infection, don't try home remedies. See your doctor. The usual treatment is antibiotics and lots of liquids

INFLAMMATORY BOWEL DISEASES/ CROHN'S & COLITIS

Catheters Ease Complications of Crohn's Disease
Tubes drain abscesses that plague sufferers, and stave off surgery

Threading a catheter through the skin to drain pelvic or abdominal abscesses in people with Crohn's disease is highly effective, and can delay or avoid surgery.

So says a new study from Massachusetts General Hospital and Harvard Medical School.
This method, called percutaneous abscess drainage (PAD), had a 96 percent success rate and postponed or eliminated the need for surgery in many of the people in the study, which appears in the March issue of the journal Radiology.

Seven out of 100,000 people have Crohn's disease, a chronic inflammatory disorder of the lower bowel and colon. It can cause abdominal pain, diarrhea, weight loss, fever, fatigue and rectal bleeding. Its cause is unknown. Between 10 percent and 30 percent of Crohn's sufferers develop one or more abdominal or pelvic abscesses, which are pus-filled pockets.

"Patients develop inflammatory changes in their intestines, which causes little perforations and abscesses to form. They commonly develop this problem," explains Dr. Melvin Rosenblatt, director of interventional radiology, Memorial Sloan-Kettering Cancer Center.

If an abscess isn't treated, it may grow and result in a dangerous spread of infection.
"The traditional way has been surgical, where you remove it, and you remove a piece of intestine. And this is an ongoing process that plagues these patients time and time again," Rosenblatt says.
While using a catheter to drain these abscesses isn't a new technique, the new study is the largest one to look at the procedure's effectiveness. In this study, the authors researched the medical records of 32 people with Crohn's disease who had the procedure at Massachusetts General Hospital between July 1985 and July 1999.
The researchers checked the medical records of the people for at least 22 months—the average was seven years—after they had the procedure.

All but 53 abscesses in the 32 people were drained adequately through the catheter, with up to 2 liters of abscess fluid drained. Half of the patients did not require surgery within two months of the procedure. Drainage continued for just over two weeks, on average.

Long-term follow-up found that seven of 31 of the patients didn't need surgery. One patient died of causes unrelated to the study. Seven of the people had a recurrent abscess—the same number that would be expected after surgery, the researchers say.
The single complication: one person developed a fistula—an abnormal passage between the abscess and the skin—after the abscess healed. It was surgically repaired.

PAD is used extensively to treat abscesses in the abdomen, pelvis and chest. It has a high success rate, can be done in a medical center's radiology suite, and is less costly than surgical drainage, the study authors say.

The PAD procedure takes 30 to 60 minutes. The patient is sedated, an ultrasound or CT image is taken of the affected area, and the entry point on the skin is injected with a local anesthetic.

A small incision is made, and the catheter is threaded through the incision. After the catheter is in place, a drainage bag is attached to the outer end. A syringe is used to remove as much material as possible from the abscess.

The tube is left in place, and the person can continue doing the tube drainage at home or it can be done by a visiting nurse.
"This study shows PAD can stave off or eliminate the need for surgery to treat abscesses in people with Crohn's disease," Rosenblatt says.

That's important because these abscesses can occur many times.
"If you can save them from having a big operation, you're doing a real good deed," Rosenblatt says.

What to Do
You can find more information about Crohn's disease at the National Institutes of Health or the Crohn's and Colitis Foundation of America. (Interviews with Melvin Rosenblatt, J.D., director, interventional radiology, Memorial Sloan-Kettering Cancer Center, New York City, March 2002 Radiology)
This article can be accessed directly at: http://www.healthscout.com/template.asp?page=newsDetail&ap=1&id=506149

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! **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 __

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 Aug. 21st starting at 3 PM

Baptist Medical Center 8th Floor
Meeting Room C

For information
Phone: 904 396-7827