May 2005 Volume 7 Issue 5

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 May 15th starting at 3 p.m.

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

2005 UOA National Conference
August 3-6 • Anaheim, CA

Anaheim Marriott
$99.00 plus tax single or double

www.uoa.org

May 15, 2005 meeting will be Mr. David Hill with Home Instead, Inc.

News from Inside the UOA Central Office

UOA has won an **Award of Excellence** in the 2005 Associations Advance America (AAA) Awards program, a national competition sponsored by the American Society of Association Executives (ASAE), Washington, D.C. UOA received the award for its **Annual Youth Rally** and the volunteer counselors and nurses who assist the rally. This program is now in the running to receive the Summit Award, ASAE's top recognition for association programs to be presented in September. Congratulations to the many Youth Rally volunteers who make this program a winner!

The **Ronald McDonald House Charities of Denver, Inc**., awarded **$5,000** to cover UOA Youth Rally expenses. We are grateful to Ronald McDonald for helping to make a difference in the lives of the campers who will join us this summer in Boulder, CO.

It's not too late to sponsor a rider in ***Get Your Guts in Gear—the Ride for Crohn's and Colitis,*** June 10–12 in New York. Click to www.ibdride.org and name one of UOA's riders: **George Salamy, Joey Wannat, Terry Italia, Hilary Maller** or **Garrett Drapala**. They need your support to reach their fundraising goals.

Join us at the UOA **National Conference August 3–6** in Anaheim and attend the special **Chapter Leadership Institute** that includes sessions on membership recruiting and retention, fund raising, newsletters, viability and revitalization, as well as the opportunity to meet with chapter officers and members in your area. Also, laff with Leff, as opening session speaker **Nancy Leff,** reminds you that, "He who laffs, lasts!"

In 2002, UOA established the **Parent's Conference Scholarship Program** to provide financial assistance to families who cannot afford to attend the UOA National Conference. Donations from UOA chapters will help ensure that families with special-needs children can meet other families in similar situations. Last year, eight families attended, thanks to your generosity. Will you again help provide the funding to bring families to Anaheim? For details, visit http://www.uoa.org/networks_parents.htm.

While you are at the conference, celebrate **Disneyland's 50th Anniversary**. More than 500 million people have visited Disneyland since July 17, 1955 when admission was $1! Special parades, a new ride and updated attractions make Disneyland the place to be this summer. It's easy to combine the four-day UOA conference with a visit to Mickey's home. You will see there is still magic after all these years.

Ostomy education is now available **en Español!** UOA's **seven patient care guides** have been translated into Spanish and are available at $3.50 each. Order a set for just $20 if your community has a Hispanic population. UOA has already distributed free copies to chapters and nurses in Southern California and Arizona, thanks to a generous grant. Texas will be next.

If you missed the March 14 UOA **Chat Room for chapter leaders**, you can find the edited transcript for that chat at: www.uoa.org/chatroom. Read about chapter promotion, program suggestions, attracting people to meetings and more.

Are you wearing your "Got Guts" Bracelet? Have you ordered your supply for your chapter? Through a generous collaboration with the Crohn's & Colitis Foundation of America, we are making packages of blue wristbands imprinted with the "Got Guts" slogan available to UOA chapters at a 50 percent discount. Order the deeply discounted bracelets from CCFA in packages of 10 to resell as a chapter fund raiser. Use the order form in the March Chapter Mailing, or e-mail nitalia@uoa.org for an electronic copy. UOA leaders and members have more guts than any group I have ever met, so wear your bracelet proudly!

Positive Options for Colorectal Cancer, a practical new book just added to the UOA bookstore, was written by Minneapolis UOA Chapter President **Carol Ann Larson**. Warning signs, screening tests, treatment options, alternative healing methods and life after colorectal cancer are all included, along with more than 12 survival stories. Available to UOA members for $12.95 from www.uoa.org.

Your chapter's voice is important so **don't forget to vote** for three available seats for the **2005-07 UOA Board of Directors**. Ballots were mailed to all chapters in early April and the deadline for receipt is June 7. For voting procedures, contact your chapter president. For candidate profiles, see the spring *OQ* or visit: http://www.uoa.org/candidatebios.htm.

Register Online

2005 UOA Young Adult Conference
http://www.uoa.org/events_yan.htm
August 3-6 • Anaheim, CA

2005 Youth Rally Applications
http://www.uoa.org/events_youth.htm?
July 10-14
San Diego State University

PATIENT'S RIGHTS

A Patient's Bill of Rights

The American Hospital Association presents a Patient's Bill of Rights with the expectation that observance of these rights will contribute to more effective patient care and greater satisfaction for the patient, his physician and the hospital organization. Further, the association presents these rights in the expectation that they will be supported by the hospital on behalf of its patients, as an integral part of the healing process. It is recognized that a personal relationship between the physician and the patient is essential for the provision of proper medical care. The traditional physician-patient relationship takes on a new dimension when care is rendered within an organizational structure. Legal precedent has established that the institution itself also has a responsibility to the patient. It is in recognition of these factors that these rights are affirmed.

The patient has the right to considerate and respectful care.

The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment and prognosis, in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in his behalf. He has the right to know, by name, the physician responsible for coordinating his care.

The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include but not necessarily be limited to the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation. Where medically significant alternatives exist, the patient has the right to such information. The patient also has the right to know the name of the person responsible for the procedure and/or treatment.

The patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his action.

The patient has the right to every consideration of his privacy concerning his own medical care program. Case discussions, consultation, examination and treatment are confidential and should be conducted discreetly. Those not directly involved in his care must have the permission of the patient to be present.

The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

The patient has the right to expect that within its capacity, a hospital must make reasonable response to the request of a patient for services. The hospital must provide evaluation, service and/or referral as indicated by the urgency of the care. When medically permissible, a patient may be transferred to another facility only after he has received complete information and explanations concerning the needs for the alternatives to such a transfer. The institution to which the patient is to be transferred must first have accepted the patient for transfer.

The patient has the right to obtain information as to any relationship of his hospital to other health care and educational institutions insofar as his care is concerned. The patient has the right to obtain information as to the existence of any professional relationships among individuals, by name, who are treating him.

The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to participate in such research projects.

The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and where. The patient has the right to expect that the hospital will provide a mechanism whereby he is informed by his physician or a delegate of the physician of the patient's continuing health-care requirements following discharge.

The patient has the right to examine and receive an explanation of his bill regardless of source of payment.

The patient has the right to know what hospital rules and regulations apply to his conduct as a patient.

No catalogue of rights can guarantee for the patient the kind of treatment he has a right to expect. A hospital has many functions to perform, including the prevention and treatment of disease, the education of both health professionals and patients and the conduct of clinical research. All these activities must be conducted with an overriding concern for the patient and, above all, the recognition of his dignity as a human being. Success in achieving this recognition assures access in the defense of the rights of the patient.

(Approved by the House of Delegates of the American Hospital Association, February 6, 1973)

CONTINENT DIVERSIONS/ RESERVOIRS

The Aging Pouch: What Happens as the Pouch Gets Older?

It has been 20 years since the ileoanal pouch was first introduced into the array of options for the surgical treatment of ulcerative colitis and familial polyposis. Over these twenty years thousands of patients all over the world have had pouch surgery and are benefiting today by having avoided a permanent iteostomy. A question mark remains, however, what will happen to the pouch as the patient and his or her pouch, gets older. Because the operation is relatively young, few patients have had their pouch for an extended period of time. Now that we are in the year 2000, it is appropriate to review what we know of what happens to the bowel that makes up the pouch, and to speculate a little about what we don't know.

The small intestine and the large intestine are very different, both in structure and in function. The small intestine absorbs small nutrient molecules from the liquid stool where as the function of the large bowel is to absorb water and to store the stool until evacuation occurs. The small bowel is long and narrow; the large bowel is short and wide. Stool passes very quickly through the small bowel, transiting its 20 feet in 2 or 3 hours. Stool passes slowly through the large bowel, taking an average of 36 hours to pass through the 6 to 7 feet. These differences in structure and function are reflected in the different incidence of cancer in the small and large intestine. Small bowel cancer is very rare, as cancer-causing chemicals (carcinogens) in the stool don't have the opportunity to cause any changes in the cells lining the bowel. In the colon and rectum, however, stool sits there and carcinogens have plenty of time to have an effect. Colon and rectal cancer is the third most common cancer in the United States.

When we make a pouch, we are changing the structure and function of the small intestine to make it work like a colon. It now stores stool and absorbs water. It comes as no surprise therefore to learn that as an ileal pouch gets older it starts to look like a colon.

Under the microscope the lining of the colon is flat. The small intestine normally has finger-like projections called villi that help with nutrient absorption. There are no villi in the colon. As pouches get older, researchers have found that they tend to lose their villi. The colon has a lot of mucus-producing cells (goblet cells), much more than the small bowel. Older pouches have increasing numbers of goblet cells. Older pouches also lose the look of small bowel and start to took like rectums. These changes usually take several years to start becoming apparent. What does this mean for the patient's state of health?

Our concern as physicians, who care for patients with pouches, is whether this tendency of small bowel pouches to become like large bowel will mean that there is a risk of cancer or "colitis" developing in the pouch. Indeed some preliminary reports suggest that in a few patients, precancerous changes can be found in cells of a pouch. Polyposis patients are certainly prone to get polyps in their pouch but nobody has reported a cancer yet. As far as colitis is concerned, we already know the syndrome of "pouchitis" that mimics colitis and can occur very early after pouch construction. This is different from a true return of colitis. There is as yet no sip of a return of true "colitis" in older pouches. Because of the theoretical risk of "colon cancer" developing in an ileal pouch we recommend that patients come for yearly pouch checks. At this time biopsies will be taken to look for "dysplasia," an appearance of the cells lining the pouch that suggests that cancer may possibly develop. As time goes by and the number of patients with maturing pouches increases the natural history of the elderly pouch will become more obvious. Stay tuned for more information.

(James M. Church, M.D, Staff Colorectal Surgeon Cleveland Clinic)

Care of the Urinary Continent Pouch

Catheterization or irrigating your urinary continent pouch requires a clean technique. Emptying takes about three to four minutes. Eventually pouch capacity allows for emptying only four to six times a day and not at all during the night. This schedule is designed to work up to that point. During the first week, catheterize every two hours during the day and every three hours at night. Increase the time between catheterizing every six hours during the day and not at all during the night. Your body will let you know if more frequent catheterization is needed. Complaints of abdominal cramping are common when pouch is full.

Always catheterize when getting up in the morning and before going to bed. Drink your liquids; never slack off your liquids to decrease urine output. Setting up a personal schedule for your lifestyle is fine, but never go longer than six hours between catheterizations.

Notify your physician if no urine drains when inserting catheter, if urine leaks between catheterizations, or if urine becomes foul smelling, thick, or cloudy. Also for fever and chills, abdominal or side pain, and blood in your urine. These are signs sand symptoms of an infection.

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
3 PM

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 May 15th starting at 3 PM

Baptist Medical Center 8th Floor
Meeting Room C

For information
Phone: 904 396-7827