April 2005

Volume 7 Issue 4

## **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

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Please plan to join us Sunday Apr. 17th starting at 3 p.m.

## ConvaTec ET Clinic Day 4/27/2005

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#### A MESSAGE FROM THE PRESIDENT

I would like to thank everyone for attending the February 2005 meeting. Our speaker was Van from Convatec. We also had four new ostomates and a told of 15 people present at the meeting so we got to get together and talk about the different problems each was having. It was a very interactive meeting.

I would like to thank our speaker is Patti Mathis, Community Hospice Volunteer. She spoke on "Caring for the Caregiver". Last year she came out and did a wonderful presentation on the "Five Wishes". She is an excellent speaker and I appreciate you all coming out to support our organization and to welcome Ms. Mathis back to speak to us. We had a new person come out. She is getting educated on becoming an ostomate as she has to face the decision very soon. I appreciate all the help I had to educate her. Thanks.

I would also like to thank each and every one of you that has contributed to the Ronald McDonald "Pop Top" collection. I empted the bags that I received from the February meeting and I can't see the bottom of the jug. So I think we just might fill that gallon jug up. Please keep on saving them and either bring the to a meeting or give them to Medical Care Products.

For our April 17, 2005 meeting, I am trying to get Hollister representative there or we will just have a group session for anyone that needs our help or assistance.

For our May 15, 2005 meeting, I have Mr. David Hill with Home Instead, Inc. Lou Ann-Marie Chamberlin referred him to us. I would like to thank her for her help in finding speakers for us. He is a representative with the company, which is a Senior Care company that provides non-medical needs for individuals in their homes. These include companionship, home help needs, visitation and sleep over services, etc. These are the kinds of things that aren't covered by medical insurance, but sorely needed by those who have a chronic illness, and/or family members, to provide relief from their day-to-day care giving responsibilities. Of course, this is an expensive service, however this information will be beneficial to know just in case you may need help. He also will be explaining the different types of "registries" out there, and both licensed and non-licensed services available to us in our community.

If anyone knows of a speaker that may like to speak at our meetings, please contact, Brenda L. Holloway, Vice President at (904) 282-8181.

Also remember that we do have a donation closet at Medical Care Products. If you have any extra or unused ostomy supplies or medical supplies, please contact Brenda and she will be glad to coordinate with you to have them pick up or you can bring them to a meeting.

Once again, thank you for your cooperation in keeping this organization active because without YOU there would not be help for ostomates in this area. Thank you.

Brenda L. Holloway, Vice President

Eugene Summerville, President

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

## MOTION TO AMEND ARTICLE 4 – DUES OF THE BYLAWS DATED MARCH 1988 AND REVISED SEPTEMBER, 1989 AND REVISED JULY 1990 AND REVISED JUNE 1, 1993

Article 4 now reads as follows:

#### ARTICLE 4 – DUES

The annual dues shall not be less than \$15.00 per member as determined by the Board of Directors or by vote of the membership and shall be payable at a renewal date each year.

The annual dues for non-voting members shall be less than \$5.00 as determined by the Board of Directors or by vote of the membership and shall be payable at a renewal date each year.

Dues shall be waived for honorary members.

Dues shall be waived for any person who expresses an inability to pay and this information shall be held confidential.

THE PROPOSED REVISION TO ARTICLE 4 SHALL BE AS FOLLOWS:

#### ARTICLE 4 – DUES

The annual dues shall not be less than 12.00 per member as determined by the Board of Directors or by vote of the membership and shall be payable at a renewal date of May  $1^{st}$  of each year.

1. The annual dues for non-voting members shall be less than \$5.00 as determined by the Board of Directors or by vote of the membership and shall be payable at a renewal date each year.

2. Dues shall be waived for honorary members.

3. Dues shall be waived for any person who expresses an inability to pay and this information shall be held confidential.

Treasurer report: \$1,324.12

## Get Your Guts In Gear IBD Benefit Ride

June 10 -12, 2005 210 miles - New York City to Saratoga Springs, NY Riders, Crew and Volunteers are needed.

http://www.uoa.org/donations\_ibdride.htm

## **Register Online**

2005 UOA Young Adult Conference http://www.uoa.org/events\_yan.htm August 3-6 • Anaheim, CA Register Online

2005 Youth Rally Applications http://www.uoa.org/events\_youth.htm? July 10-14

## 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: <u>http://www.healthscout.com/template.asp?page=newsDetail&ap=1&id=506149</u>

## Eye Inflammation and Bowel Disease

A specific type of eye inflammation can sometimes be associated with Crohn's disease and, to a lesser extent, ulcerative colitis. The connection between collagen diseases and eye inflammation is well known, particularly with rheumatoid arthritis. This would suggest a relationship between eye inflammation, arthritis and inflammatory bowel disease (IBD).

EPISCLERITIS – With this condition, there is a localized, red raised area in the conjunctiva. The deeper vessels are engorged in the episclera, which is the layer above the white sclera. Pain is often severe and aching in nature. This disease can be recurrent but is easily treated and is not threatening to sight.

SCLERITIS – This is a deeper localized inflammation. Pathologically it consists of a central mass of necrotic collagen with elongated cells. This picture is identical to rheumatoid arthritis. This more severe condition can be threatening to sight. Episcleritis is often treated with topical steroids and can be easily controlled. Scleritis usually requires systemic steroids and recently the use of nonsteroidal and anti-inflammatory drugs (NSAIDS) has been found helpful. Side effects of steroids are well known. In the eye they can cause cataracts and raised intraocular pressure, so NSAID use is increasing. Salicylates (aspirin) have been around for a long time, but new uses have been found for their anti-inflammatory properties. Other groups in this category are phenylalkanoic acids such as Naprosyn, acetic acids such as Indocid or Voltaren. Other groups used are fenamic acids and enolic acids such as Butazolidin and Feldene.

PUNCTUAL OCCLUSION – Patients using corticosteroid drugs can prevent a lot of systemic absorption and limit side effects by pressing on the lacrimal sac, between the inner corner of the eye and the bridge of the nose after instilling the drops. This prevents the drop passing down the tear duct where it is readily absorbed. This trick is also very useful in patients using glaucoma drops such as beta blockers.

IRITIS – This is an eye inflammation that can be acute or sub-acute. It involves the iris, which is the pigmented tract. One variety, HKAB27, can be present in arthritis and gastrointestinal disease. In some patients with ulcerative colitis, an ostomy resolves the ocular disease, however, it may not prevent recurrences of ocular inflammation.

(Dr. Gordon Hamilton, Consultant Ophthalmologist)

## **PSYCHOLOGICAL ISSUES**

Be Compassionate To Those Dealing With Loss and Grief

Grief and loss are inevitable parts of living. Eventually everyone will experience a loss. Maybe it will be the loss of a job, a marriage, health or the death of a loved one. Whatever the loss, it is followed by sadness and suffering. When death occurs, friends often describe feeling helpless. Based on my professional experience as a nurse and my personal experience after the death of my husband, I offer suggestions on how to support a grieving family.

An initial reaction is to bring food to the family. If friends are not careful, though, the amount of food can be overwhelming. Having someone organize a meal schedule is helpful and prevents multiple dinners from arriving on the same night. The meal doesn't have to be fancy. I remember my children cheered when a pizza delivery truck arrived at our house. Label your dishes or bring disposable ones. The need for food doesn't end after two weeks. Meals delivered months later are wonderful as are gift certificates to restaurants or an invitation to join you for dinner. The first few days to weeks after the death of a family member are numbing. Many people must be notified and a million decisions must be made. You can provide assistance by doing laundry, walking the dog or taking the children for a few hours. Try to allow the grieving family some quiet time each day.

Many people, children and adults alike, don't know what to say to someone who is grieving. People are afraid they will say the wrong thing and often what you want out say may come out wrong. A heartfelt and simple "I'm sorry for your loss: along with a hug might be the best words and actions. Don't say you know how they are feeling because chances are, you don't. No two losses are the same and they should never be compared. If talking is hard for you, send a note that expresses your feelings. Some of the cards I received after the death of my husband related stories and memories. I am thankful people are willing to share those stories with my family. Often we are unsure of how to acknowledge a birthday or holiday. A phone call, visit or written note to the family is best. Families like to know that you have not forgotten their loved one. Include the grieving family in a holiday celebration. Occasionally a family may choose not to celebrate or celebrate in a very different manner. Be supportive of their choices and allow for new traditions to be developed.

Reluctance to talk with a bereaved person is often because we don't want then to cry. Do not be afraid of tears. In grief they are crying inside. Your words and hugs bring those inside tears to the outside. Tears are healing. I remember talking about my husband and tears flowed. My friend said, "I'm sorry I made you cry." I replied, "You didn't make me cry – I cry every day."

In conclusion, an important way to help a grieving family is to be a compassionate friend during good times and the inevitable sad times we all encounter in life. Compassion, which means to suffer with, will provide love and support to a grieving family. Love and support will help the family incorporate the death into their lives and move forward.

(Dale Mayer, MSU News Service, Benefis Healthcare Supplement 3/02)

## **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\$7.50**. 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.** 

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Phone: (904) 733-8500 Fax: (904) 733-8700 Email: patti@ostomymcp.com T 0 :

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