May 2004 Volume 6 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

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

Medical Care Products, Inc
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WE ARE ON THE NET
www.ostomymcp.com

A MESSAGE FROM THE PRESIDENT & VISITATION COORDINATOR

I would first like to thank everyone that attended our meeting on April 28, 2004. We had 14 people attend and out of that 14, 3 were new people and we enjoy having new faces and hope that they will return in the future. We had Van from Convatec as our speaker and he introduced the new product that they now. Van is always very informative on all the Convatec products and answers all questions. We hope that next time he comes to speak we have a bigger turn out.

We also had a report from Eugene on Ron Perry. He is doing better but still need to gain some weight before he can have his next surgery. He is very alert and would love to have visitors if you can just stop by. He is in the Shands pavilion in room 344.

Also we need everyone to check and see if they have renewed their national and local membership. If you become/renew your national & local membership, you will receive this newsletter and the Ostomy Quarterly magazine. I just received my Spring 2004 issue and read it from cover to cover then I pass mine on to a new member. Please contact Brenda (282-8181) and I will check and see if you are still current on your membership.

We also want to remind you that if you have extra supplies and want to donate them to our closet that we have at Medical Care Products, please contact Brenda (282-8181) and I will arrange to either pick them up or you can drop them off at Medical Care Products. You never know your extra supplies could help someone get thru one month.

Our next meeting is May 16, 2004 and we will be playing UOA jeopardy with Patti from Medical Care Products as the host. They played this game back in June 03 and everyone loved it so please plan on attending.

I had at least 5 people call me with regard to our meetings and our organization and out of the five, three attended our April meeting. Again I thank you for attending.

I hope to see each and every one of you on May 16, 2004 at 3:00 p.m. at Baptist Medical Ctr, 8th Floor, Function Room C.

Sincerely, Brenda L. Holloway, President and Visitation Coordinator

Minutes of the April, 2004 meeting of the United Ostomy Association Jacksonville Chapter #211

The meeting was brought to order by President Brenda Holloway at 3:07pm

Vice President made the announcement that Ron Perry was doing much better and is in room #344 of the Pavilion at Shands Medical Center.

Brenda announced that she had several calls with new ostomates interested in our programs. Several new folks were in attendance at this meeting.

Brenda introduced Van Russell, Territory Manager for Convatec. Van talked about several new products available from Convatec. He showed us the Invisiclose pouch. This drainable pouch does not have a separate tail closure. The tail rolls up on itself and securely closes without the hard plastic closure we are all used to. He also re-introduced the Esteem Synergy line of two-piece products. This system is a very low profile two-piece that does not have a hard plastic ring flange. It is very discreet. It includes drainable pouches with and without filters. The line also includes a moldable convex wafer along with the flat stomahesive flexible style. The urostomy pouch should be available this year.

As always, Van's presentation was appreciated and interesting.

The door prizes were distributed and the 50/50 drawing put $5 into the treasury.

The meeting was adjourned for refreshments at 4:28pm.

Respectfully submitted,

Patti Langenbach, Secretary

UOA Annual Youth Rally

July 10-14, 2004

The **UOA's Annual Youth Rally** provides the opportunity for 11 to 17 year-olds to be with others their age who have had ostomy or alternate-procedure surgery. Sessions on hygiene, self-care, sexuality and other suitable subjects are offered. The volunteer staff includes WOC(ET) nurses and UOA members. The rally usually is held in a university setting and teaches young people that the only thing limiting them is their attitude, not their ostomy. For additional information, view the UOA Youth Rally Brochure http://www.uoa.org/new/files/youthrally.pdf (278K PDF)

For more information, call 800-826-0826, ext. 104 or e-mail jsmith[at]uoa.org.

Inflammatory Bowel Diseases—Misery Needn't Be the Norm

A bout of diarrhea is unpleasant enough. Imagine chronic diarrhea. It's a very real problem for the more than 1 million Americans who have inflammatory bowel disease (IBD). The most common forms of IBD are Crohn's disease and ulcerative colitis.

Although a cure for these diseases remains elusive, the goal is to make it possible for people with IBD to have normal or near-normal lifestyles.

Damaging Inflammation

Chohn's disease and ulcerative colitis are two separate inflammatory diseases that damage the digestive tract lining. The course of either disease can be variable and difficult to predict. Signs and symptoms may subside, only to be followed by periods of long-term flare-ups.

Crohn's disease can occur anywhere in the digestive tract. It may occur simultaneously in different locations. However, when it's limited to the colon, it's referred to as Crohn's or granulomatous (gran-u-LOM-uh-tus) colitis. Crohn's disease generally penetrates every layer of tissue in the affected area.

Ulcerative colitis is typically found in the colon and rectum. The inflammation often begins in the rectum and spreads into the colon. It usually affects only the innermost lining of the colon and rectum, not the deep tissues. Over time, it may increase the risk of colon cancer.

IBD can occur at any age, although the peak for it to appear is between the ages of 15 and 35. What causes Crohn's disease and ulcerative colitis is unknown. It's thought that genetic predisposition plays a role; along with some sort of environmental trigger that sets the diseases in motion.

Diagnosing the Problem

Generally, several tests are needed to confirm whether you have Crohn's or ulcerative colitis. Blood tests may detect inflammation. Two newer tests check for the presence of antibodies that may differentiate Crohn's disease from ulcerative colitis. The new tests are called perinuclear anti-neutrophil cytoplasmic autoantibody (pANCA) and anti-Saccharomyces cerevisiae antibody (ASCA). However, the results are only 70 percent to 80 percent accurate.

Diagnostic imaging of your intestines can provide helpful information. Colonscopy – viewing the entire colon using a thin, flexible tube with an attached camera – is generally the most informative imaging technique. Biopsies taken during colonoscopy can help in diagnosing IBD.

Drug Treatment Options

Drug therapy is a key component to treating IBD. Although it's not a cure, it often helps control the condition. Once the right drug or combination of drugs is determined, symptoms can often be reduced. But is may take some time. Medications that may be considered include:

***Anti-inflammatory drugs** –* These often are prescribed first in the treatment of IBD. They act *like a salve by working on the lining of the intestine. These drugs include balsalazide (Colazal), mesalamine (Asacol, Pentasa, Rowasa), olsalazine (Dipentum) and sulfasalazine (Azulfidine). Another type of anti-inflammatory drug – corticosteroids (such as prednisone, methylprednisolone, and hydrocortisone) may be used for moderate to severe IBD that doesn't respond to other treatment.*

***Immune modulators** – These medications are used to bring an overactive immune system back to normal. The most widely used are azathioprine (Imuran) and 6-mercaptopurine (60MP, Purinethol). Infliximab (Remicade) was approved by the Food and Drug Administration for short-term treatment of moderate to severe Crohn's disease, but newer studies indicate that it's effective over the long term as well. Methotrexate is another option when other drugs fail to provide relief. The drug cyclosporine also may be used by people who don't respond to other medications.*

***Antibiotics** –* Metronidazole (Flagyl) and ciprofloxacin (Cipro) may be helpful in *treating abscesses and fistulas associated with Crohn's disease. In some instances, metronidazole and ciprofloxacin may provide benefit for Crohn's disease even in the absence of fistulas and abscesses. However, side effects may prevent their long-term use.*

Continued on page 4

In some situations, nicotine skin patches may be used for short-term relief of ulcerative colitis flare-ups. It's not clear why the nicotine patch has this effect. Depending on your symptoms, your doctor may recommend the use of other medications. These may include anti-diarrheals, acetaminophen (Tylenol), iron supplements, and vitamin B-12 injections. In addition, a number of other experimental drugs are being tested for IBD.

LLifestyle Treatments

Lifestyle changes that may help control your symptoms and even lengthen the time without symptoms include:

Manage your diet – *Although there's no firm evidence, some foods – such as dairy products and fatty foods – appear to aggravate IBD in some people. You may want to try eliminating certain foods for a period of time to see if that brings relief. To make up for lost nutrient, ask your doctor whether you should take a multivitamin. Supplements of any sort should be taken only under your doctor's supervision. Some can interfere with other medications.*

Drink plenty of fluids – Drink at least eight 8-ounce glasses of fluid (water is *preferable) a day to offset fluid loss from diarrhea.*

Reduce and manage stress – Although stress isn't a cause of IBD, it can worsen signs *and symptoms. Counter stress with daily exercise, rest and relaxation techniques.*

Connect with those who can help – Consider joining a support group. The Crohn's and *Colitis Foundation of America (CFFA) has chapters around the country. CCFA's toll-free number is 800-932-2423. The Web site address is www.ccfa.org.*

Avoid non-steroidal anti-inflammatory drugs (NSAIDs) – NSAIDs, including ibuprofen and naproxen, which may aggravate symptoms.

Surgical Treatment Options

If you have ulcerative colitis, there's 20 percent to 39 percent chance you may need surgery at some point. Removal of the colon and rectum – proctocolectomy – can be a cure for the disease and reduces the risk of colon cancer. One method involves attaching the last portion of the small intestine to a small opening (stoma) created in the lower abdomen. An ileostomy pouch worn over the stoma collects waste and is emptied as needed.

An alternative surgical procedure eliminates the need to wear a pouch. In this procedure, the colon and inner lining of the rectum are removed and a portion of the small intestine is redirected, reshaped, and attached to the anus so that near-normal stool passage is possible. This is called ileoanal anastamosis. Other names are "J" pouch or ileoanal pouch.

The chances you'll need surgery are much higher with Crohn's. At least 70 percent of those with the disease need at least one or more surgeries. These surgeries generally involve removing a portion of the small or large intestine affected by the disease. This sometimes results in years of improvement or even no symptoms. However, the disease often shows up at another point in the digestive tract.

(Mayo Clinic Health Letter, Mayo Foundation for Medical Education and Research, Rochester MN, 55905)

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

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

MEETINGS ARE HELD AT THE
BAPTIST MEDICAL CENTER
8TH FLOOR - MEETING ROOM C -
3RD SUNDAY OF EACH MONTH
3PM

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TO:

Join us
Sunday May 16
starting at 3 PM
Baptist Medical Center 8th Floor
Meeting Room C

For information
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