

Ostomy Association

"We help ourselves by helping others to help themselves."

of the Houston Area

We are a volunteer-based organization dedicated to providing education, information, support and advocacy for people who have had or will have intestinal or urinary diversions.

P.O. Box 25164 Houston, TX 77265-5164 www.ostomyhouston.org

Monthly support and information meetings are held in three locations for member convenience.

Central Group

Monthly: Third Monday
Time: 7:00 p.m.

Place: American Cancer Society Building

6301 Richmond Avenue, Houston

Contact: Terry Marriott 713-668-8433

marriott@rice.edu

Meeting: Monday, May 18, 2009

Program: Guest Speaker: Janet Davis, CWOCN

Skin and Wound Care Division (3M Authorized Consultant)

Baytown Group

Monthly: First Monday

Time: CHANGE —7:00 p.m. (Please note new time!)
Place: Community Room in Lobby of San Jacinto

Methodist Hospital

4401 Garth Road, Baytown

Contact: Cindy Barefield 281-420-8671

Meeting: Monday, May 4, 2009

Program: Billing Medicare Allowables, an update by

Jenny Jansson-Smith, RN, CWCN, COCN,

with Sterling Medical Services

Patient Visiting and Support Services

Doctors and ET Nurses, please note:

Upon request from a doctor or nurse, a specially trained visitor will be sent to visit an ostomy patient before and/ or after surgery. The visitor will be matched as nearly as possible according to sex, age, and type of ostomy. There is no charge for this service. The visitor does not give medical advice. Please contact our Visitor Coordinator, Dorothy Andrews at 713-789-4049.

We are a health support group, a non-profit, tax-exempt, organization of volunteers whose purpose is to provide mutual aid and education to persons who have ostomies and to their families. We are a Texas non-profit corporation. Membership fees and donations are tax deductible.

Northwest Group

Monthly: Tuesday following the third Monday

Time: 7:00 p.m.

Place: NW Medical Professional Bldg.

(The Cali Bldg.)

17117 Cali Drive, Houston (This location is just off of 1960 and west of I-45. Turn north on Cali Drive from 1960. At the stop sign turn left on Judiwood and left again to park behind the Cali

Building.)

Contact: Tony Romeo 281-537-0681

sa1tmr@sbcglobal.net

Meeting: Tuesday, May 19, 2009
Program: Take Steps Re-Cap

J-Pouch Group

Monthly: Third Monday Time: 7:30 p.m.

Place: American Cancer Society Building

6301 Richmond Avenue, Houston

Contact: Ron Meisinger 281-491-8220

Meeting: Monday, May 18, 2009
Program: General Discussion

Happy Mother's Day!

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Central Group News

We had 23 in attendance at the Central Group Meeting on Monday April 20. Robert F. Gagel, MD gave us an extremely interesting presentation about how our bodies respond to various chemicals such as steroids, especially cortisone, aka, prednisone, prednisolone, etc, to cause "Glucocorticoid-Induced Osteoporosis". He made the point that all our soft body organs require specific minimum amounts of calcium and vitamin D to operate properly and that our bodies will resort to leaching calcium out of our bones to try to maintain the necessary level of calcium to run our nerve synapses and other systems that require calcium to work properly if that calcium level drops too low. Unfortunately, cortisone in its various namesake forms does cause calcium loss in our bones when we take it in therapeutic large doses to reduce the inflammation due to Crohn's, Ulcerative Colitis, and various other diseases that do respond favorably to corticosteroids. He also explained that bones are live body structures that are actively changing as long as we are alive and contain specific cell types that perform these processes. He defined some of the bone specific nomenclature on a slide.

Osteoclasts are bone cells that destroy damaged bone as in breaks and prepare bone surfaces for repair; these also may be partially responsible for bone mass density, BMD, loss due to therapeutic corticosteroid dosing.

Osteoblasts are bone cells that build up bone as in healing fractures, and in restoring BMD after corticosteroid use has stopped; although he said we never seem to get as much BMD back as we lose.

Osteonecrosis is bone death often occurring in the jaw bone and has been shown to be linked in a very small percentage of patients to use of bisphosphonates such as Fosamax which are prescribed to help prevent loss of BMD and possibly osteoporosis. Scientists are not sure why this happens, but it may have some sort of genetic link.

He also gave us a website where we can go to calculate our bone Fracture Risk Assessment using our personal information and our BMD information from any bone density tests we may have had; the website given below will assess the probability that you will have a fracture due to bone loss in the next ten years (esp., a hip fracture).

 $Go\ to:\ http://www.shef.ac.uk/FRAX/index.htm$

Then, click on the Calculation Tool button so you can put in the data so you can calculate your Fracture Risk Assessment. The site also has definitions and other information about BMD and fractures. We wish to thank Dr. Gagel for taking the time to give us this very informative and helpful presentation.

We are going to have an election during our May meetings at the Satellite Groups as well as the Central Group for some of our Directors whose terms are expiring. Laura Beth Jackson has resigned due to family responsibilities keeping her out of town; Laura Beth worked very hard fielding calls from people wanting to donate supplies and collecting those supplies so that we could distribute those supplies to ostomates who at least temporarily cannot afford to purchase them. Kathleen Duplessis whose term expires this year does not wish to continue as a Director due to her increased job responsibilities; Kathleen has worked hard as our Membership Chair since the Fall of 2005 when the United Ostomy Association disbanded and we reorganized as the Ostomy Association of the Houston Area and elected a Board of Directors. We thank Kathleen and Laura Beth for their service to our organization. Below is the list of nominees preceded by the year their term will expire after being elected.

- 2011 Margie Tucker, new Director replacing Laura Beth Jackson
- 2012 Clarice Kennedy, new term, continuing Director
- 2012 Mary Harle, new term, continuing Director
- 2012 Ron Cerreta, new Director replacing Kathleen Duplessis

Next month's presentation will be given by:

Janet Davis, CWOCN Skin and Wound Care Division (3M Authorized Consultant) on Monday, May 18 at 7:00 p.m.

See you all there,

Terry Marriott

We encourage you to bring your spouse or significant other and members of your immediate family to our meetings.

The United Ostomy Associations of America (UOAA) can be contacted at www.uoaa.org.

Disclaimer: The information contained within this newsletter is presented expressly for informational purposes only and may not be applicable to everyone. It should not be substituted for professional medical care or attention by a qualified practitioner. Always check with your doctor if you have any questions or concerns about your condition.

Baytown Group News

Results of our recent member survey were discussed. Overall consensus of those who took the time to write, e-mail or phone was that the support group serves a vital purpose and should be maintained. The challenge for many members is to make the time to attend each month. The group felt like 7:00 p.m. is a more manageable meeting time rather than 6:00 p.m. There was also a suggestion that nursing staff from the local Home Health agencies be invited for presentations by the ostomy vendors so they could benefit from the updates.

The group had decided to focus the roundtable discussion on **Ostomy Survival Kits** after one member's experience in a local restaurant. You may have worked through this scenario on your own, but here are the ideas from our group:

- Shape of bag affects storage of spare ostomy wafer and pouch. Square or rectangular such as a woman's cosmetic bag seems to work best. One member had purchased a small 6" square bag for about \$2 at a local discount store. Perhaps vendors could provide an on-the-go pouch rather than a large utility type bag for new ostomates.
- Roll of tape may be helpful but one or two of the stickers that come with each box of pouches with filters can seal a hole and are much less bulky than a roll of tape!
- Compact disposable bags and pre-moistened wipes are great for large clean-ups when the sink and trash can are not available. (These items may be found on the newborn care aisle at the store.)
- Extra clamp (To replace a faulty integrated closure or a clamp that has failed.)
- Choose the handicap stall in the restroom if possible for your repairs. This will give you more room to work.
- Look for a hook on the back of the bathroom stall door. This may hold your purse (ladies), your involved clothing or some of your survival kit contents.
- Another idea that may help you avoid the use of your Ostomy Survival Kit altogether is to pay close attention to any "pre-leak" symptoms that you may experience. One member described this as an "itchy feeling that begins under the wafer" and is followed by failure of the wafer if he ignores it.

If you have an idea for the ostomy survival kit that we have not included, e-mail Baytown Group Coordinator, Cindy Barefield RN, WOCN, at cbarefield@tmhs.org. We would love to hear from you.

Time change once again for the Baytown Group 1st Monday, back to 7:00 pm. Hope to see you there!

Cindy Barefield, RN, WOCN 281-420-8671

Northwest Group News

The Northwest Group had 17 attendees at our April meeting. Our scheduled speaker Terri Anderson from Massage Oasis was unable to be with us. This absence allowed for an unscheduled roundtable discussion event. We enjoyed each others' company and explored the entire range of ostomy topics from the perspective of a fresh new ostomate to the experience of more seasoned veterans. Three new members were represented and recognized for their first meeting.

After breaking into smaller groups to discuss target issues, we rejoined into a larger group to discuss the upcoming World Ostomy Day in October and its photo contest sponsored by Hollister. The deadline for photo submissions is August 1, 2009. Our group decided to participate in the upcoming Take Steps fund raising event benefitting Crohn's and Colitis research. Our WOCN Pat Thompson was the first to step up and commit.

We began preparing right away for the walk event by consuming all the outstanding refreshments. Suzanne provided an array of delicious bakery goodies. Martha brought a '49ers cake from an old family recipe and Gay Nell added in chocolate chip cookies.

Gay Nell Faltysek 281-446-0444 **Tony Romeo** 281-537-0681

Project Cure

The Commission on Urgent Relief & Equipment (aka Project CURE) was founded over twenty years ago to address the need for medical supplies, equipment and services worldwide. Since it began, Project CURE has delivered medical relief to people in over 120 countries.

Equipment and supplies are donated weekly, sorted and catalogued by volunteers and then provided according to pre-accessed need via large cargo containers. Collection and volunteer centers are located all over the United States, including a CURE location here in Houston. The Ostomy Association of the Houston Area will from time to time deliver excess donated supplies to them.

Operations Director Lane Gibson advises "The supplies you donate to Project C.U.R.E. allow us to 'Deliver Health and Hope to the World'. We are able to give healthcare professionals in developing countries the supplies and equipment they need to care for their patients."

To learn more about Project Cure, visit their website at www.projectcure.org or call at 832-251-2489.

Who Are We?—The Series Mary Harle



"I'm just a kitchen person, I like to be doing something" states Mary Harle. Mary is active in her church, support group and community. She enjoys providing administrative support at the church and participating in their home visitation program.

Mary is a strong member of our association and is currently holding three positions, Vice President of the Board of Directors, Telephone Coordinator and Supply Coordinator. As the Vice President, she functions as the hospitality coordinator for the Central Group by scheduling refreshments for meetings throughout the year. Mary often provides tasty treats herself and enjoys greeting people at meetings.

In her Telephone Coordinator role, she contacts members of the Central Group by phone before meetings to provide a reminder and program information. Mary also acts an outreach extension to check on members and see how they are doing.

Mary's newest role is Supply Coordinator. She is responsible for working with others to maintain ostomy supplies stored at two locations. Supplies are received from estate donations and individuals.

Supply requests are evaluated on a case by case basis. A request can be made by contacting Mary or Clarice Kennedy, another member of the Board of Directors. Examples of past request circumstances are a lack of finances, surgical aftercare or during catastrophic events like Hurricane Ike. Supplies are inventoried, and twice a year or more as needed, the excess is donated to Project CURE.

Mary had her surgery in 1996 and was later referred to the ostomy association by her physician. Her advice to new ostomates is that there is a life after surgery, that life goes on, that there is no real difference, and to just take things day by day. She feels the greatest gift she has received since her ostomy was to become a part of a wonderful support group full of caring and understanding friends.

Take Steps for Crohn's and Colitis

Take Steps for Crohn's and Colitis in Houston will take place on May 16, 2009, between 5:30–8:30 p.m. at Stude Park in the Heights. It is a casual walk for two miles and a great opportunity to share with others.

The Ostomy Association of the Houston Area is forming a team and will be participating. Aside from the community

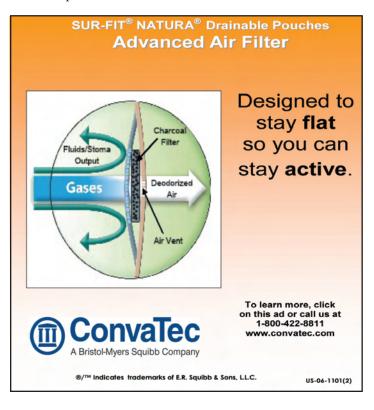
spirit and outreach, this event will raise awareness of Crohn's & Colitis. Over 1.5 million children and adults are afflicted with a digestive disease nationwide. Approximately 24% of all ostomy surgery is related to Crohn's and Colitis, also known as Inflammatory Bowel Disease (IBD).



Lauren R. Menard, Walk

Development Manager, shares that "anyone can participate in Take Steps for Crohn's & Colitis, including people of all ages and fitness levels. Thousands of walkers, teams and sponsors will participate in more than 50 cities throughout the country." Ms. Menard works with the Houston Gulf Coast South Texas Chapter of the Crohn's & Colitis Foundation of America.

This event includes mascots, face painters, bounce houses, food/drink, a Mission & Advocacy Center and Resource Fair. Come join us at the walk or support someone who is walking to make a difference. Registration and donations can be made via the internet at www.cctokesteps.org/houston, select Join a Team or Donate to a Walker, then select our team by the name "Ostomy Association of the Houston Area" or you can contact Pat Thompson, RN,CWON at 713-822-3172 for assistance.



Opportunities and Announcements

Anniversary Gift

As you celebrate the anniversary of your ostomy surgery each year, consider making a monetary gift to the Ostomy Association. Checks should be made payable and sent to:

> Ostomy Association of the Houston Area Attn: Lorette Bauarschi, Treasurer P. O. Box 25164 Houston, TX 77265-5164

Memorial Fund

Donations can be made to our Memorial Fund to memorialize or honor individuals. Checks should be made payable and sent to: Ostomy Association of the Houston Area

> Attn: Mary Harle P. O. Box 25164 Houston, TX 77265-5164

(When sending a donation, be sure to include the name of the person being honored so that appropriate acknowledgement can be sent.)

Donation of Supplies

We are contacted on a regular basis by individuals who are in need of donated ostomy supplies. Consider donating ostomy supplies that you no longer use to assist your fellow ostomates in the Houston area. Please contact Mary Harle at 713-782-7864 with any questions.

It's All Here! The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more. Half of each subscription funds the nonprofit United Ostomy Associations of America - the only national organization providing vital information, resources, support and advocacy for ostomates. **Annual subscriptions: \$25 (4 issues)** Send check or money order to: The Phoenix, P.O. Box 3605, Mission Viejo, CA 92690. Phone/Fax: 949-600-7296. Name Address Apt/Suite City State E-mail UOAA Donation (optional)

Consultation with ET

Clarice E. Kennedy, Certified Enterostomal Therapist, is available for consultations. Clarice is an ostomate with over 30 years of knowledge and experience to share with anyone who has questions about, or needs assistance with, the care of an ostomy both prior to and following surgery. Contact cekennedy1@peoplepc.com or call 713-647-8029.

Sponsorship

You can sponsor a member of our ostomy support group with a tax-deductible donation to cover the cost of their membership. Send your check in the amount of \$25.00 to:

Ostomy Association of the Houston Area Lorette Bauarschi, Treasurer P. O. Box 25164 Houston, TX 77265-5164

Use Those Shopping Cards

Kroger and Randalls return a percentage of your purchases to the Ostomy Association on a quarterly basis. For card applications, contact Ed Wood at 281-493-5015 or ewood6@comcost.net.

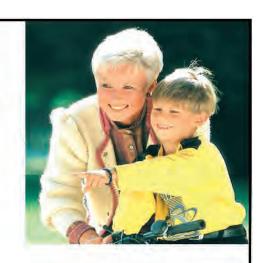
Moving?

Our newsletter is sent by bulk mail, which the Post Office will not forward even if you fill out a forwarding request. To continue receiving the newsletter after a move, contact Lorette Bauarschi, Treasurer, at 713-460-1955 or lbauarschi@sbcglobal.net or send your request to the Ostomy Association of the Houston Area, P. O. Box 25164, Houston, TX 77265-5164.



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For a Free Sample or For More Information Contact Clarice Kennedy, CET (713) 647-8029 or cekennedy1@peoplepc.com

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_ as a donation to support the association's mission of helping ostomates.

Membership Application

I have enclosed an additional \$____

Membership in the Ostomy Association of the Houston Area requires one easy payment. Please complete the following form and mail as directed with payment as shown.

Dues of \$25.00 per year are payable to:

Ostomy Association of the Houston Area, Attention: Treasurer

P	O. Box 25164, Houston, TX 7	7265-5164	
			Date:
Name:		Phone:	
Street Address:			
City:	State: ZIP	: E-mail:	
Surgery Date:	Birth Date: _		
Reason for surgery: □ C	ohn's 🗆 Ulcerative Colitis	□ Cancer □ Birth Defects □ Oth	ner
Procedure or Relationshi) :		
To help us complete our re	cords, please answer the follow	ving. <i>Check all that apply.</i>	Membership benefits include:
□ Colostomy	□ Continent Ileostomy	□ Parent of Child with procedure	Monthly Support/Information
□ Ileostomy	□ Continent Urostomy	□ Spouse/Family Member	Meetings, Social Events,
☐ Urinary Diversion	□ Pull-Through	□ Physician	Monthly Newsletter
□ Other:		□ Nurse	
□ I would like to attend	I meetings with the (please cir	rcle one):	
Central Group	Baytown Group	Northwest Group J-Pouch	n Group
□ I would like to becom	ne a member but cannot pay c	lues at this time. (This will be kept confi	âdential.)
I learned about the Ostom	y Association from		
□ ET Nurse □ Ph	ysician 🗆 Newsletter 🗆	Surgical Shop □ Website □	Other:

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