

## Ostomy Association of the Houston Area

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

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

#### The Importance of Education

by Lisa Gausman, edited by Patti Suler

I have had 15 abdominal surgeries and hospitalizations with stays ranging from a few days to one as long as 11 months. I was finally diagnosed with Crohn's Disease after several misdiagnoses. I felt emotionally and physically ripped apart. I started off with a temporary colostomy, then a temporary ileostomy, then a permanent colostomy resulting in a fairly good run of five years where I was able to return to the workforce.

One day without warning, I was taken from work to the hospital because three fistulas broke through my abdominal wall. When Doctors were unable to repair the damage, I was admitted to the ICU and my husband and parents were called in to potentially say their goodbyes. 11 months hospitalization with three geyser-like fistulas, a stoma from my old colostomy site and a newly functioning ileostomy. The reparative surgery later left me with less than five feet of G.I. tract total, resulting in short-gut syndrome and a jejunostomy.

People knew my Crohn's Disease was in remission and assumed I should be "normal," healthy and happy. To the contrary, the emotional isolation was enormous, my body-image was shattered, I was no longer able to work as my bathroom frequency ranged between 25-40 times daily. My perception of how my

#### What is a Jejunostomy?

In my case, a jejunostomy is another TYPE of ostomy. There are colostomy, ileostomy, jejunostomy and urostomy. So it is just the stoma placement. My stoma is formed from the jejunum not the colon or ileum. So it is not a feeding tube spot, it is an ostomy type, jejunostomates are always short—gut also known as Short bowel syndrome (SBS). —Lisa

husband could possibly see me as he did before was a hurdle too high for me to get over.

I was also told that motherhood was not possible because of extensive scar damage done to my reproductive organs from the numerous perforations, blockages and surgeries.

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.

Still, in the year 2000, my husband and I decided to try to have a baby. We signed up at the In Vitro Fertilization clinic. I was such a high-risk that I was required to have a Doctor's approval for pregnancy care. My husband and I tried seven offices and no one would take me on. I went in tears to my surgeon who had first diagnosed me and he signed off.

I began taking my IVF medications and soon came to the realization that my short-gut was hindering my ability to absorb them. The Doctor tripled the dosage and we began again. I produced viable embryos and two were implanted resulting in pregnancy. My pregnancy was filled with complications. One morning at 7 months, I awoke 20 pounds heavier than when I had gone to sleep—hypertension had set in and the baby needed to come out. Thus on a quiet Sunday morning, my son was born 8 weeks early, weighing 3 pounds, perfect, and to my surgeon's dismay is not named after him!

Throughout my many surgeries and long-term hospitalizations, I struggled with drug dependency (addiction). I had always been on pain killers of some sort as well and struggling with depression.

(Continued on page 4)

#### **Patient Visiting and Support Services**

Doctors and WOC 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, Marian Newman at 713–392–5768.

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#### **Central Group News**

We had 15 members attending and two visitors at our February meeting. Our speaker was Kerrianne Pelzl with Convatec. She brought the one piece Moldable, the Accordion Flange, and the latest urostomy pouch with the Moldable technology. We also got to view and examine some Ostomy Secrets products. Kerrianne gave away a couple of the Ostomy Secrets wraps and had coupons toward the products. She had samples of the Diamonds gel forming deodorant packets and adhesive remover. Meeting with the representatives of the products we use is a great way to find out what is new and to give them feedback. The manufacturers welcome suggestions and complaints which may improve their products so this is our opportunity to be heard.

Coming in May, we will field a team in the Crohns and Colitis Take Steps walk. Contact Patti Suler or Paul Batchelder to join the team. Of course, donations are welcome, too.

We are looking for a newsletter Editor. Email and web access along with an eye for articles of interest to our members is all that is needed.

October 3 is World Ostomy Awareness Day. What should the organization do for this day? Please contact me with your ideas.

The Ostomy Association of the Houston Area (OAHA) has been in existence for 59 years. That is an enormous achievement for any group, but for an all-volunteer group with a hushed up subject like ours, it is amazing. Fifty-nine years ago there was no internet so the main means of finding information about this surgery was your doctor or the library. As wonderful as many of our doctors are, they don't have a clue as to how to manage an ostomy day to day. Libraries are wonderful, too, but for very specialized knowledge, difficult to manage. So, one on one, ostomates in Houston found one another. About this time, a new nursing specialization was created for ostomies and wound care, Enterstomal therapists and later Wound Ostomy Continence certified nurses. For many, these nurses made the difference between living normally and not venturing out of the house. The Ostomy Association of the Houston Area has had the support of many ETs and WOC nurses over the years. We are grateful to them. However, for many of us, meeting and talking with someone with the same surgery is invaluable. What we may have thought was just our problem is also someone else's and, whoopee, they know how to solve it. When we might have been apprehensive about traveling with our ostomy, it is a relief to find that others have traveled the world and adventured in many ways. Please join us in celebrating 59 years of the Ostomy Association in Houston next month. One of our past presidents, Terry Marriot, will give a presentation that tells about what the organization does, how it is set up, and a little of the history. Next year, we will have our 60th Anniversary. We are looking for volunteers to help make that celebration a great one. Please contact me if you would like to help.

Regards,

#### **Denise Parsons**

President, OAHA, 713-824-8841

#### **Baytown Group News**

"Ostomy Pouches & Wafers: Making the Most of Features Available to You!" was the topic of discussion for support group meeting in February. Using a show-n-tell approach, the group was able to see and compare features of pouching systems from various companies with Cindy Barefield, RN, CWOCN as facilitator. Advantages and disadvantages for items such as drainable and non-drainable pouches were presented. Considerations for the use of high volume pouches and one piece versus two piece systems helped some members see when specific options would be most helpful. Wafers are available in cut-to-fit, moldable and convex varieties. An epiphany for the evening came from one gentleman who realized that although he is satisfied with his current pouching system; comparing these products is a great way to stay updated on what is available should you need to make a change in the future!

March 2 is our next scheduled meeting. We will have Tabatha Schroeder, RN, BSN, CWOCN, with Coloplast join us. Hope to see you as well.

Take care of you and yours,

Cindy Barefield, RN, CWOCN 281-428-3033

## CROHN'S AND COLITIS TAKE STEPS WALK

Saturday, May 2, 2015

To walk with us or donate http://online.ccfa.org/goto/OAHA2

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

**Osto Group** www.ostogroup.org

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UOAA

The United Ostomy Associations of America (UOAA) can be contacted at: www.uoaa.org Or 800-826-0826

#### **Northwest Group News**

Coloplast representative Tabatha Schroeder provided updates on how the new Mio was doing and advised they are planning to expand the successful line with a convex version. She shared samples of the accessories and demonstrated how they felt on the skin. We also got a look at the new filter system. This one is supposed to be tops.

Changes, Changes, Changes

The next Northwest group meeting will be at the old location on a new day. Mark your calendars for Wednesday, March 18, 2015, 7:00 pm, at the original Cali Professional Building complex. March's program will be comprised of an 'Ask The WOC Nurse' round table. This is a great opportunity to get information.

#### **Tony Romeo**

936-588-4031

#### **Local OAHA Upcoming Elections**

Ron Cerreta, Mary Harle, June Huber, and Patti Suler have been nominated to serve on the Board of Directors. Nominee(s) will be voted on at the May OAHA meetings.

## Do you have a way with words? Editing Help Needed

Please consider volunteering to serve as editor for this monthly newsletter. The job involves collecting meeting information from the groups (by email), providing articles (original or from archived newsletters), and sending information on to the graphic designer. No design work is involved for the editor. If you would like to know more, please contact Patti Suler at 281-352-2566 or pattiksuler@aol.

#### **WOC Nurse Directory**

Cindy Barefield, RN, CWOCN (281) 428-3033 Houston Methodist San Jacinto Hospital

cbarefield@houstonmethodist.org

Charlene Randall, RN, CWOCN (713) 465-8497

Specialty Wound & Ostomy Nursing, Inc. charlene@swoni.com

Pat Thompson RN, BSN, CWON (281) 397-2799 Pat.thompson@tenethealth.com

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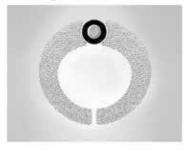
For free samples call 1-877-858-2656 or visit us online at www.sensuramio.us

#### New features:

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#### **Visitor Training**

Twelve gathered to enjoy the visitor training this past Saturday (02/21/15). Held at the Northwest Group facility, the training was fun. Blending new and old, the information was smoothly offered and digested. The free lunch was good too. Please note, even if you are not current in your visitor status or you see someone outside our established referral process—please let Marian or Carol know. Keeping tabs on who we help allows us to improve on how we help others.



Visitor Training Attendees



June H.



AIR.

Ed W. and



#### The Importance of Education

(Continued from page 1)

Finally I hit rock bottom with an overdose. I spent 4 days in an addiction boot camp at the Peter Lougheed Centre (one of five Calgary hospitals) and came out clean. I had spent so many years, just managing my disease and my ostomy and never accepting it and certainly never talking about it, that I was buried under the stigma which I self-inflicted.

I came alive in so many ways. I got clean, I had a renewed clarity and I had purpose. Now nobody can get me to shut up about all of this. My motto has become: Ignorance comes from the lack of knowledge therefore we must spread the knowledge.

#### **Titles and Positions**

Lisa Gausman, Vice President Calgary Ostomy Society, Vice President NCACOA, Senior Editor Ostomy Canada magazine, Editor Changing Times

Excerpts of Lisa's story are reprinted with permission from Ostomy Canada magazine.

## **Get Ostomy Answers!**

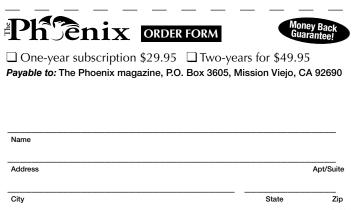
The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more.

Subscriptions directly fund the nonprofit United Ostomy Associations of America – the only national organization providing vital information, resources, support and advocacy for ostomates.



Billy L

Carol J.



#### **Central Group**

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

Place: American Cancer Society Building

6301 Richmond Avenue, Houston

Contact: Denise Parsons 713-824-8841

rockynme2@aol.com

Meeting: March 16, 2015 Program: Roundtable

#### **Baytown Group**

Monthly: First Monday Time: 6:00 p.m.

**Place:** Community Room in Lobby of Houston Methodist

San Jacinto Hospital 4401 Garth Road, Baytown

Contact: Cindy Barefield 281-428-3033

Meeting: March 2, 2015

Program: Guest Speaker: Tabatha Schroeder, RN, BSN,

CWOCN, with Coloplast

#### **Northwest Group**

**Monthly:** Third Tuesday of the month

**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 936-588-4031

sa1tmr@sbcglobal.net

Meeting: WEDNESDAY, March 18, 2015

Program: "Ask The WOC Nurse" Roundtable

#### J-Pouch Group

**Monthly:** Third Monday

**Time:** 7:00 p.m. or by Appointment American Cancer Society Building

6301 Richmond Avenue, Houston

**Contact:** Ron Cerreta 832-439-1311

Ron Meisinger 281-491-8220

Meeting: March 16, 2015

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

#### **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 to the *Ostomy Association of the Houston Area* and sent to the Treasurer at the address shown below.

#### **Memorial Fund**

Donations can be made to our Memorial Fund to memorialize or honor individuals. Checks should be made payable to the *Ostomy Association of the Houston Area* and sent to the address below. When sending a donation, be sure to include the name of the person being honored so that acknowledgement can be sent.

#### 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 Ron Cerreta, Treasurer, at 832-439-1311 or texasronc@aol.com or send your request to the provided address below.

#### For Anniversary Gifts, Memorial Donations, Mailing Changes, or Sponsorships, please send all correspondence to:

Ostomy Association of the Houston Area

Attn: Ron Cerreta, Treasurer

P.O. Box 25164

Houston, TX 77265-5164

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

#### **Use Those Shopping Cards**

Kroger and Randalls return a percentage of your purchases to the Ostomy Association on a quarterly basis. For information about shopping cards, please visit the website:

http://www.ostomyhouston.org/

#### Sponsorship

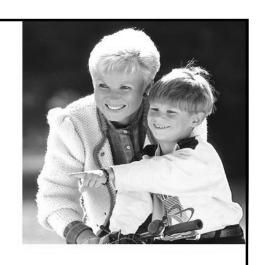
You can sponsor a member of our ostomy support group with a tax-deductible donation to cover the cost of their membership. Please make the check in the amount of \$25.00 payable to *Ostomy Association of the Houston Area* and send to the treasurer's address above.

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.

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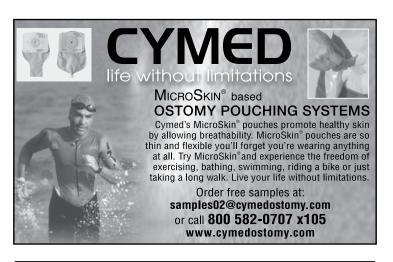




For a free sample or for more information, please call Jenny Jansson-Smith, RN, CWON at 512-992-7703 or send email to JennyMJanssonS@stomocur.com

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Membership Application				
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 77265-5164  Date:				
Name:		Phone:		
Street Address:				
City:	State: ZIP:	: E-mail:		
Surgery Date:	Birth Date:			
Reason for surgery:   Crohn's   Ulcerative Colitis   Cancer   Birth Defects   Other  Do you speak a foreign language?   Yes   No Foreign language spoken:  Procedure or Relationship:  To help us complete our records, please answer the following.   Check all that apply.  Colostomy   Continent Ileostomy   Parent of Child with procedure  Membership benefits include:  Membership benefits include:  Membership benefits include:				
•	□ Continent Urostomy □ Pull-Through	□ Spouse/Family Member	Monthly Support/Information Meetings, Social Events, Monthly Newsletter	
☐ I would like to attend meetings with the <i>(please circle one)</i> :  Central Group Baytown Group Northwest Group J-Pouch Group				
□ I would like to become a member but cannot pay dues at this time. (This will be kept confidential.)				
I learned about the Ostomy Association from  □ WOC Nurse □ Physician □ Newsletter □ Surgical Shop □ Website □ Other:				
I am interested in volunteeri	ng. □ Yes □ No			
I have enclosed an additional \$ as a donation to support the association's mission of helping ostomates.				







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#### Finally, an ostomy pouch filter that works!

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