



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

My Story, A Stoma's Perspective

By Patti and Junior Suler

Appeared in the Summer 2015 issue of Ostomy Canada magazine.

My story is full of twists and turns (intestinal humor). All good stories begin at a point of great sadness or elation, wonderful enrichment, classy humor or somewhere in between. My story has it all, so where do I begin? This is an ostomy story, so it seems fitting to hear it from Junior, my stoma. —PS

Mom was very sick, so much so, she didn't know how sick she really was. Diagnosed with Ulcerative Colitis in 2004 at the age of 44, she was actually excited to hear that the disease had a name. She believed that now that she knew what was wrong, that it could be fixed. Sadly as the case is with most Inflammatory Bowel Disease stories, it was not so simple.

She struggled with medications, diets, tests and diarrhea for the next two years. Her personal health log reflected bathroom trips between 15 to 30 times daily. Losing approximately 40 pounds due to malabsorption, she underwent numerous diagnostic colonoscopies. She even began providing her own custom music

CDs to staff as she entered the procedure room. Although she could not hear the music, she wanted everyone to be relaxed so that only their best work was done.

It was Friday the 13th in January 2006. Her colon perforated during the fourth colonoscopy procedure. Her large intestines were so diseased and damaged that they just shredded. It was her luckiest day as she realized later she could have experienced the perforation any time, anywhere, yet here she was—surrounded by trained medical personnel.

My name is Junior and I was created that day. Mom went in on Friday and went home with me, her new stoma, on the following Tuesday. We felt so much better after being so sick for so long. We could eat!

The surgery was dirty from the perforation and her belly looked like a lobster tail split open. It took six months for the wound to close completely healing from the inside out. Also, I was a tiny flush mounted guy and required a lot of finesse to pouch. Convexity became my best friend and Eakin rings my brother, but

(Continued on page 3)



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.

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

In This Issue	
My Story, A Stoma's Perspective	1 & 3
Group News	2-3
WOC Nurse Directory	4
Meeting Dates/Times	5
Advertising, Support	5-7
Membership Information	7
Contact Information	8

Patient Visiting and Support Services

Doctors and WOC Nurses, please note:
Upon request from a doctor, nurse, or social worker, a specially trained visitor will be asked to contact an ostomy patient by phone or visit them in person before and/or after surgery. The visitor will be matched as nearly as possible according to sex, age, and type of ostomy. The visitor does not give medical advice, and there is no charge for this service. Please contact our Visitation Coordinator, Marian Newman at 713-392-5768.

Central Group News

At our May 16 meeting, we welcomed Dr. Marium Murad, the founder of the Movement is Blessed program. Movement is Blessed is a specific exercise technique which is designed to increase circulation. You can find out more information on this program from Dr. Murad's website, www.movementisblessed.com.

NEWS ON PROPOSED CHANGES TO MEDICARE-HANDLING OF OSTOMY SUPPLIES

RJ Poonawala, from Spring Branch Medical Supply, also stopped by to provide us with some information about the proposed changes to the way ostomy supplies will be handled by Medicare. RJ visited with the Baytown group earlier this year and Cindy Barefield provided the following informative summary (lightly edited by me), which I think is important enough to run again:

RJ came to talk with the group about Medicare's expansion of the competitive bidding program. From the Centers for Medicare & Medicaid Services website, I pulled this basic information: The Durable Medical Equipment, Prosthetics, Orthotics and Supplies (DMEPOS) Competitive Bidding Program was mandated by Congress through the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. The statute requires that Medicare replace the current fee schedule payment methodology for selected Durable Medical Equipment, Prosthetics, Orthotics and Supplies items (which could include ostomy supplies) with a competitive bid process. RJ is active in the DME community, and as an advocate for ostomates and others who currently have options for medical supply coverage, there is concern for the impact of competitive bidding on our ability to continue to choose the ostomy supplies we wish to use and the ability of suppliers to continue to stock all of the supplies they currently do if insurance will not reimburse for such supplies. This will affect not only Medicare patients but the privately-insured as well. Durable medical suppliers believe that competitive bidding is in the President's budget now and could be signed before the election, but there is uncertainty as to whether it would pass Congress.

The UOAA, CCFA and other relevant organizations have already contacted Congress to object to these proposed changes. RJ promised to continue to update us with relevant information on this topic which is of vital concern to ostomates.

WELCOME TO NEWLY-ELECTED BOARD MEMBERS

I am happy to announce that our members have elected the following people to serve a three-year term on our Board of Directors: Denise Parsons, Marian Newman and Tony Romeo. Be sure to thank them for agreeing to serve.

CCFA TAKE STEPS WALK ON MAY 14TH

Terry Marriott and I were honored to represent the Ostomy Association of the Houston Area at the annual CCFA Take Steps

Walk on May 14th. The walk was in the early morning hours at the Houston Zoo, and they had a record turn-out, raising over \$113,000. We handed out our newsletters and UOAA booklets on ileostomies and other information that new and potential ostomates would find useful. We were happy to be able to provide this important educational material to "help ourselves by helping others to help themselves."

NURSING SCHOLARSHIPS

We are so happy to announce that in commemoration of our 60th anniversary, the OAHA has agreed to donate \$2,000 per for the next five years to the WOCN Society to fund a scholarship for a nurse who plans to work in the Houston area. We are very excited about being able to do this. The OAHA believes one of the most important persons in a new ostomate's life is his or her nurse, and if we can do anything to encourage nurses to get this specialized training, we are very happy to do so. We also believe our group is instrumental in educating and providing support to all ostomates. We hope the scholarships will serve to remind the WOC nurses that we are here to help them in the work they do. And even more good news! When I announced our scholarship donations at our May meeting, RJ from Spring Branch Medical Supply generously offered to match our gifts! We would like to thank Pat Thompson, who is helping us work out the details with the WOCN Society.

JUNE MEETING

Our next meeting is on June 20. Our speaker will be Dr. Brian Keith Bednarski, Assistant Professor, Associate Program Director Complex General Surgical Oncology Fellowship, University of Texas MD Anderson Cancer Center. See you in June for our first meeting of the summer!

Regards,

Lorette Bauarschi, President, OAHA, 713-582-0718

Northwest Group News

Over a dozen were present for the May meeting which combined our second supply swap meet and an excellent program by Kris McNeill with Hollister. We welcomed a new pre-surgical mate and relative. Hollister has a lot of new pouches and products. All in attendance were full of questions and seeking samples. The Swap Meet was fun and many people were able to take home items they already used or wanted to try. Next month our program will be presented by Peggy Smith, MS, RD, LD, Clinical Dietitian.

Our continued thoughts go out to Suzanne, GayNell, Paul, Gen, Jay, Jane, Craig, Billy, and all the rest. We hope to see you at our Ice Cream Social in July.

Tony Romeo 936-588-4031

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

Baytown Group News

Baytown Support Group met in May with Kris McNeill, Ostomy Sales Specialist for Hollister as our presenter. Kris shared with the group that Hollister made the decision to update their new wafer with consideration of a survey which revealed that about half of those living with a stoma will have peristomal skin issues at some point in their lives. Skin problems SHOULD NOT be a normal part of living with a stoma. Hollister's goal is to help maintain healthy peristomal skin from the start!

The new skin barrier is called CeraPlus. This barrier (or wafer) contains ceramide which is a naturally occurring lipid in the skin and protects against dryness. Ceramides help prevent water loss that can lead to skin damage and dryness. You may have used a lotion that contained a ceramide.

In a product evaluation in 2015 involving 193 participants, 82% of clinicians reported they were likely to continue to use and

recommend the CeraPlus Skin Barrier to their patients. Hollister has incorporated the barrier into many of their one and two piece pouching systems and hopes to have it available for Urostomy soon.

Kris also told us about the new soft convex extended wear barrier (wafer). The one piece has belt loops which can be very helpful in getting a snug fit with a difficult stoma. Another helpful upgrade: new design of the filter no longer requires that a sticker be placed over it when showering!

Baytown Ostomy Support Group will meet again on the 2nd Monday in June (the 13th). We are planning to have Dr. Naveed Zafar, Surgeon at Houston Methodist San Jacinto Hospital join us. I hope you will make plans to attend!

Cindy Barefield, RN, CWOCN
281-428-3033

My Story, A Stoma's Perspective *(from page 1)*



pouching had its problems. I could spring a leak turning, bending, sitting, laying—well you get the idea.

We also learned that the original diagnosis of Ulcerative Colitis was muddled a bit as the colon autopsy leaned towards Crohn's. The options for a J-pouch were now off the table and the ten inches of rectum left behind as a place holder were no longer needed and

would pose problems later on.

Mom returned to work after six weeks and began educating everyone about stomas. She shared the good news with everyone just like a newly born stoma evangelist. Waitress, guy waiting at the elevator, pre-meeting warm up and parking attendant—no one was safe from hearing the news of what happened. Over the top! Her family gently let her know that not everyone needed to know about me right away, that maybe she needed to save some information for later or never.

She participated in monthly support groups and really enjoyed having others like her around. She launched and maintained a personal support web site and newsletter named after me "Junior's Corner" for about five years.

She had a few more surgeries. A life-changing one was my revision to improve pouching and wear time. Now I could go out and play just like all the other stomas.

Mom says I went from being a cocktail wiener to a big beef eater size!

Another surgery was done to remove my cousin 'Left Behind' (rectum). A final surgery addressed a leakage problem in my old exit strategy (anus) left by cousin Left Behind.

Comparing herself to other mates, mom felt like a slow learner and the journey seemed long and difficult. Secretly, she wondered when she would feel like her ostomy was not driving her life. When would all this new stuff become second-hand? Patience, she heard that a lot. Everyone was different, everyone had a different path.

Mom feels that her transition was finally successful in 2011. Five years after her initial surgery, she took a vacation all by herself—to Hawaii from Texas. Planes, transfers, security, luggage, taxis, hotel, swimming, hiking, snorkeling, shopping—all kinds of new adventure rolled into one trip. She even took me up to the top of Diamond Head—hours away (she is a slow walker) from the restroom at the bottom.

She came back with a self-confidence that will never be taken away. Mom was infused with a new life perspective. She became a Master Gardener, joined a community organic garden, volunteered to be the newsletter editor for her local chapter, volunteered for landscaping projects, upped her church volunteer role, functions as trained ostomy visitor, and continues her photography passion.

One of the most rewarding things she does is helping other ostomates and their families adjust to the new challenges. She smiled broadly when told a husband was advising his wife with her new ostomy—"don't fret, look what all Patti does!"





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WOC Nurse Directory

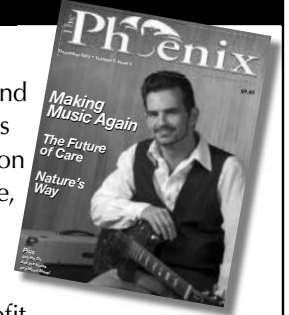
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Specialty Wound & Ostomy Nursing, Inc.
charlene@swoni.com

Pat Thompson RN, BSN, CWON (281) 397-2799
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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.



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Central Group

Monthly: Third Monday of the month
Date: **June 20, 2016**
Time: 7:00 p.m.
Place: Tracy Gee Community Center, 3599 Westcenter Drive, Houston, Texas 77042, (713) 266-8193
Contact: Denise Parsons 713-824-8841
 rockynme2@aol.com
Program: **Guest Speaker: Dr. Brian Keith Bednarski**, Assistant Professor, Associate Program Director Complex General Surgical Oncology Fellowship, University of Texas MD Anderson Cancer Center.

Baytown Group

Monthly: Second Monday of the month
Date: **June 13, 2016**
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
Program: **Guest Speaker: Dr. Naveed Zafar**, Surgeon at Houston Methodist San Jacinto Hospital

Northwest Group

Monthly: Third Wednesday of the month
Date: **June 15, 2016**
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
 saltmr@sbcglobal.net
Program: **Guest Speaker: Peggy Smith, MS, RD, LD**, Clinical Dietitian

J-Pouch Group

Monthly: Third Monday of the month
Date: **June 20, 2016**
Time: 7:00 p.m. or by Appointment
Place: **Tracy Gee Community Center, 3599 Westcenter Drive, Houston, Texas 77042, (713) 266-8193**
Contact: Ron Cerreta 832-439-1311
 Ron Meisinger 281-491-8220

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

Opportunities and Announcements

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/>

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@gmail.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.)

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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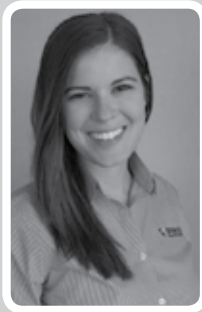
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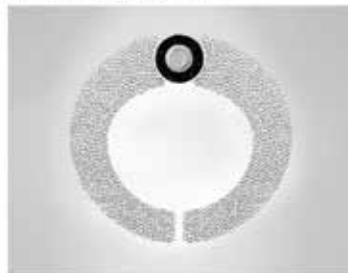
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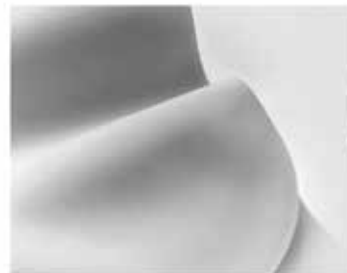
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Membership in the Ostomy Association of the Houston Area requires one easy payment. Please complete the following form and mail as directed with payment as shown. Dues of **\$25.00 per year** are payable to:
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*Membership benefits include:
 Monthly Support/Information
 Meetings, Social Events,
 Monthly Newsletter*

I would like to attend meetings with the (**please circle one**):
 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 volunteering. Yes No

I have enclosed an additional \$_____ as a donation to support the association's mission of helping ostomates.