

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

Ostomy Association 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

Mary Harle Retires from the OAHA Board



If you have attended one of our OAHA Holiday Dinners at the Junior League, you know Mary Harle. Mary is a strong and inspiring member of our association. She has volunteered and held many different positions over the years, including serving as Vice President, Supplies Coordinator (we used to have a supply cabinet) and most recently as our Phone Coordinator. So, many

of you probably either spoke to her on the phone or received a voice mail from Mary reminding you of an upcoming meeting. In her Phone Coordinator role, she would contact members of the Central Group by phone before meetings to provide a reminder and program information. This allowed her to act as an outreach extension to check on members and see how they were doing. Mary always provided us with updates at our monthly meetings and she never missed a meeting! You could always see Mary quietly greeting and welcoming every new member. We don't know what we would do without her!

We are also very grateful to Mary for hosting our annual Holiday Parties at the Junior League where we enjoyed great fellowship, food and a wonderful holiday atmosphere. And, for many years, Mary also has graciously offered her home to host Board meetings (and she bakes cookies for us as well!).

Mary had her surgery in 1996 and was later referred to the ostomy association by her physician. Her advice to new ostomates is that

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, or newmarian@gmail.com.

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.

A BIG THANK YOU to Mary for her service and her generosity. We are so happy she will continue to be involved with the Ostomy Association of the Houston Area.



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.

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Central Group News

The Central Group enjoyed visiting with Amber from Ostomy Diaries during their May Zoom Meeting. Amber's mission is to share her story and educate, encourage, and inspire others with IBD and ostomies. Amber had a complete colectomy in 2016. A year later she had the option of a reversal of her ostomy and decided to keep it! Amber got her life back with her ostomy and never looked back. She shared some of her early dating stories, how she stays hydrated, and how she organizes her ostomy supplies using an 'over the door' shoe organizer. Amber is married, she teaches high school biology and chemistry and is currently a graduate student pursuing a Masters degree in Secondary Education. We thoroughly enjoyed our visit with Amber. She is a shining star and her presentation was inspirational.

Central Group In-Person Monthly Meeting June 21st, 2021: We will be meeting at the Tracy Gee Community Center at 7:00 pm. Please join us at our first in person meeting in more than one year! We will meet and greet all guests and host a round table with tips and tricks used by some of our seasoned members and offer a Q & A. Masks are optional. Please bring your own beverage or snack as we will not be serving anything at this meeting. All are invited and if you cannot make it, please feel free to join one of the virtual June meetings listed in this newsletter. Hope to see you on June 21st!

As of May 2021: Harris County Public Health has lowered the county's Covid-19 threat level to moderate (yellow). Under this level, people are advised to be vigilant but otherwise return to normal. "Public health recommendations remain in place," unless you are fully vaccinated.

The votes are in and we want to welcome Allison Rosen to the OAHA Board and welcome back Mike McGinity. Mike is currently our treasurer and we are thrilled he will continue his valuable work with us. We want to welcome new board member, Allison Rosen and her ostomy, Fill. Allison works in cancer prevention and her goals are to educate, advocate and collaborate in an effort to spread awareness about colorectal cancer and save lives! Allison is featured in The Phoenix magazine's Summer 2021 on the following podcast <u>me+ Talk</u> with Allison Rosen. She is a great spokesperson for the ostomy and cancer community.

Houston does not have an ostomy clinic but now you can contact the ConvaTec me+ team and request a virtual meeting with an ostomy nurse who will help you with any issues you might have. Contact them at: 1-800-422-8811.

Pay it forward with our Visitor Training Course scheduled for Saturday, July 17th from 8:30 am – 1:00 pm at the Tracy Gee Community Center, 3599 Westcenter Drive, Houston, Texas 77042. If you are comfortable with your ostomy and want to help other ostomates, please join us. You need to RSVP to me at Kothleen. duplessis@outlook.com or call me 713-299-3180. We are planning on making a video recording of the training which we will share with our affiliated groups. So, if you cannot make it to the training, you can do it at a special virtual meeting so, stay tuned!

Hope to see you soon!

Kathleen Duplessis, President, OAHA, 713-299-3180

Sugar Land Group News

On Thursday May 20th, we had our exciting and engaging ostomy support group meeting via WebEx. Our topic for this month was the use of tape or other adhesive products to help secure ostomy appliances. Many products were mentioned that can be used to prepare and safely remove the adhesives from the skin. Many of the attendees joined in to give recommendations and tips of information they have learned over the years. After the presentation, we then had an open round table discussion on multiple topics including swimming, showering, and more vigorous activities, and recommendations of ostomy appliances to use.

One of our newest members informed the group that the National UOAA Conference would be held in Houston, at the Royal Sonesta near the Galleria on August 11-13, 2022, and encouraged all the individuals in the group to attend.

Next month on June 17th from 6-7 pm, we will have a guest presenter from Trio Ostomy, to share all the different products they provide. Participants will receive samples of the Trio Ostomy Products mailed to their address. **To RSVP**, **please email your name**, **phone number**, **email address and physical address**, **to Joan Burnham RN OCN at jmburnham@houstonmethodist. org or call Joan at 281-274-0188**.

Joan Burnham, MSN, RN, OCN, RN-BC, Oncology Nurse Navigator 281-274-0188 jmburnham@houstonmethodist.org

Northwest Group News

We enjoyed speaker Lisa Gausman, Senior Magazine Editor of *Ostomy Canada*, who joined us from her home in Calgary via Zoom. Almost two dozen of us participated as Lisa took us on a personal tour of what it was like to live a bountiful and rich life after 17 plus surgeries and overcoming the expectation of a lifetime being on TPN. She learned to gain weight while on TPN and now is sustaining herself through eating alone. She explained her use of a central port to provide her with life sustaining minerals and nutrients and the actual knowledge that short bowel syndrome did not mean an absence of small intestines but had other causes as well.

Her candor and humor was contagious and she extended a personal invitation to ostomates to write and submit their own stories for publication consideration as each of us is important and has a story to share. A wonderful evening for all indeed.

Our June meeting will feature one of the popular vendors and we are discussing an in-person meeting for our July Ice Cream social.

Billy Locke, 337-515-6354

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

HOPE—TCH Woodlands, Pediatric Group News

The HOPE group will not be meeting in June. You are welcome to join the Sugar Land Group Virtual Meeting on June 17, 2021.

MaryAnne Lewis, maryannelewis@hotmail.com or 281-948-1490

Baytown Group News

Virtual offering for Baytown Ostomy Support Group was offered once again on May 17.

These virtual sessions feel much like the time we spend getting used to a new pair of shoes. With some shoes, the fit is simply impossible, we give up and wonder why we bought them! With others, we try them on again and again until we begin to feel a comfort level that will let us keep them on all day. Our support group meetings are no different. There are several in our group who keep coming back and sampling these virtual sessions. Some signed in on the first day and never had a problem. Some of you do not feel a comfort level with virtual meetings—that is understandable and we hope to see you soon!

May was an opportunity for Roundtable. We were fortunate to have an ostomate who is a novice having just had his surgery a few months ago and an ostomate who has many years of experience. We talked about varied resources and these two were able to share information in a meaningful way.

WOC Nurse shared a favorite resource developed by North Texas Wound and Ostomy Nurses with the group: *10 Ostomy Resources Nurses and Patients Will Love*. Ray shared one of his favorite websites that he found helpful: <u>https://www.inspire.com/</u>

Best wishes for an enjoyable summer. We continue to hear good news about more vaccinations and fewer coronavirus infections. Hoping that this will bring us back together very soon. In June, we are looking forward to Shannon Triplett from Coloplast for the meeting on Monday the 21st.

Best regards,

Cindy Barefield, BSN, RN-BC, CWOCN

281-428-3033, cbarefield@houstonmethodist.org

2021 Annual Membership Dues Drive

The OAHA is an association of volunteers dedicated to serving and educating ostomates and their families within the greater Houston community. Thanks to the dues and donations we receive we are able to continue our outreach with monthly meetings, a certified visitor program training, monthly newsletters, fellowship and a website. In July we will be asking you to please renew your memberships. If you are not a member, we invite you to join us. Annual membership dues are \$25. If you would like to be a member, but cannot afford the membership dues at this time, please contact me directly at <u>Kathleen.duplessis@outlook.com</u>, 713-299-3180 as we receive donations from generous donors who support our mission of helping ostomates. All information is confidential.

What Can I Do With A Urostomy? What <u>Can't</u> I Do?

Don't let an ostomy stop you from having some summer fun

By Annemarie Finn, from UOA.org

When I received my bladder cancer diagnosis and the treatment plan, a radical cystectomy with an ileal conduit, I was devastated. Like so many, I went through many stages: Denial, Anger, Bargaining, Sadness and Depression, and finally, Acceptance. It felt like a double whammy. It seemed like the "cure" was worse than the disease. I would be forever changed. It was hard to wrap my brain around. It is one of the reasons I decided to write



about my experience. I had no idea what to expect and did not know where to turn. I saw some videos of survivors with ileal conduits but, I did not relate with the speakers. They were 20-30 years older than I was. I really did not want to envision a life as an elderly person before it was time.

I can use a public restroom without having to sit on the gross toilet!

What would my quality of life be? I was terrified that life, as I knew it was over. Would I be able to work? What activities would I be able to do? What would I never do again? I had so many questions and fears.

So, what can I do now that I have a urostomy?

Honestly, I can do everything I could do before. When you first get out of surgery, you are hardly able to walk around your room. When you go home, the end of the driveway is a monumental trek. By persevering and trying to walk more everyday, I was able to go from measuring distance in feet to measuring in miles. Today, I try to walk 5-10 miles a day! I have hiked intermediate trails in the hills of Eastern Massachusetts. I have discovered miles of trails in my hometown that I didn't even know existed. I am probably healthier than I was before I got sick.

Can you take a bath?

People often ask if you are able to bathe with a bag. It is very nerve wracking initially to expose your stoma. They are fairly active. I call my stoma, Squirt, when he (yes, it's a he) acts up. He does

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What Can I Do With A Urostomy? What Can't I Do? (continued from page 3)

spray urine. Picture a male toddler squirting. That's what it's like. We have no control over it. That's why we wear a pouch.

As you can see, a urostomy after a radical cystectomy is a life changer, but in a good way.

You can wear your urostomy bag in the shower. You do not need to cover it or keep it dry. It is a good idea to dry the skin around it with a hair dryer on low when you are done. You can even take your bag off and shower without it. I am over two years out from my surgery and that is how I prefer to do things on my change day. I change my bag every 3 days. I prepare all of my materials (bag, ring, barrier, paper towels, remover spray) then remove my bag. I then take a shower. I wash the skin around the stoma with just water or soap for sensitive skin. Just make sure you do not leave behind any lotion or any residue that would affect the barrier sticking to your skin. I keep paper towels ready to catch any drips when I am done and dry the skin with a hair dryer on the cool setting. I then just put on my prepared bag. I have some skin issues and find this helps with the itching and discomfort. It feels so good not to have the bag on for a while.

What about swimming?

I am a water rat. I can be in the water for hours, literally hours. It doesn't matter if it is in the ocean, a lake, or a pool. I have done them all. Personally, it has not affected the amount of time I am able to wear a pouch. I am still able to go 3 days. I am able to swim, kayak, and paddleboard with my urostomy. I even just float. It has not interfered with my love of water at all. Even better, I can wear a regular bathing suit. I have worn tankinis for years, and not because of my urostomy. I no longer have a toned teenage body. I don't even have a toned 30 something body. I like 2 piece tankinis as they hide a multitude of sins. After I got my urostomy, I decided to buy regular 2 piece bathing suits. Ironically, I am much more comfortable with my new imperfect body than I ever was before. My family laughs at me because, where I was self-conscious before, I now show off my body. Maybe it was having so many strangers looking at my most intimate body parts in the hospital or maybe I am proud of my battle scars. You cannot see my bag with my bathing suit on. It's honestly no big deal.

There are so many other things I have been able to do since my urostomy. I ride my bike. I participated virtually in the Norton Cancer Institute Bike to Beat Cancer, a 35 mile bike ride. I did it in steps but I gave myself a pass since it was only months after my surgery. I garden, do yard work, spread mulch, work, travel, you name it. As you can see, it has not limited me in any way. Because of my urostomy and thanks to my night bag, I can sleep through the night without having to get up to use the bathroom. That means I can drink up until I go to bed! I can sit through long car rides and movies with said night bag. I can use a public restroom without having to sit on the gross toilet! I can write my name in the snow!!! That is not conjecture, I actually did it. My sex life is good. I am planning a European vacation. Both of those will be the topics of future blogs.

What about what I can't do?

The list of what I can do is long. What about what I can't do. I can't pee like I used to. I am careful about lifting. I had a hysterectomy with my radical cystectomy so no more children for me. Since I was in my late 50s when I had my surgery, it's not really an issue but, I am trying to be honest here. That is something to consider if you are younger. Definitely talk to your doctor if you want children. I can't play the piano, but I couldn't before. That's about it.

As you can see, a urostomy after a radical cystectomy is a life changer, but in a good way. You can still do what you did before and even try new things. Even better, it is a life saver. Go out and live your best life. That's what I am doing.

PAY IT FORWARD WITH OUR VISITOR TRAINING

Saturday, July 17, 2021 8:00 a.m.–1:00 p.m.

Tracy Gee Community Center 3599 Westcenter Drive Houston, Texas 77042

The OAHA uses the guidelines of the UOAA and offers this program every other year. This is in person training, masks are optional. For those not able to make the trip to the Tracy Gee Community Center we will video record the training so our Northwest, Baytown and Sugar Land affiliates can become certified visitors. Our trained and certified visitors perform a very valuable outreach to the greater Houston Ostomy Community, plus we have fun getting together during our training! Please join us in July.

Please RSVP: Kathleen.duplessis@outlook.com or 713-299-3180.

Ostomy Association of the Houston Area

Central Group

Date:	Monday, June 21, 2021		
Time:	7:00 p.m.		
Place:	IN PERSON MEETING, Tracy Gee Community		
	Center, 3599 Westcenter Drive, Houston, TX 77042		
Program:	Roundtable. Masks are optional. Please bring your own		
	beverage or snack as we will not be serving refreshments		
	at this meeting.		
Contact:	Denise Parsons 713-824-8841 rockynme2@gmail.com		

Baytown Group

Date:	Monday, June 21, 2021		
Time:	6:00 p.m.		
Place:	Virtual Meeting (Current Baytown Support Group		
	members have been invited.)		
Program:	Speaker: Shannon Triplett from Coloplast		
Contact:	Cindy Barefield, CWOCN, 281-428-3033		

Northwest Group

Date:	Wednesday, June 16, 2021		
Time:	7:00 p.m.		
Place:	Virtual Meeting (Contact your group leader for login credentials.)		
Program: Contact:	Guest Speaker: Vendor Billy Locke 337-515-6354		

Sugar Land Group

Date:	Thursday, June 17, 2021		
Time:	6:00 р.т.		
Place:	Virtual Webex Meeting (Information is provided in		
	the email of your May Newsletter.)		
Program:	Presentation by Trio Ostomy		
Contact:	RSVP to Joan at 281-274-0188 or		
	jmburnham@houstonmethodist.org		
Contact:	Joan Burnham, MSN, RN, OCN, RN-BC,		
	Oncology Nurse Navigator (info above)		

Woodlands Pediatric Group

Date:	No meeting in June—Join one of the available group
	meetings this month.
Contact:	MaryAnne Lewis, maryannelewis@hotmail.com or
	281-948-1490

J-Pouch

For J Pouch questions, attend any of our group meetings, or call or text Ron Meisinger at 281-491-8220

Opportunities and Announcements

Use Those Shopping Cards

Kroger (LB326) and Randalls (3698) 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.

AmazonSmile

On your first visit to AmazonSmile (smile.amazon.com), you are prompted to select a charitable organization from the list of organizations. You can change your selection at any time. To change your charitable organization: Sign in to smile.amazon.com on your desktop or mobile phone browser. From your desktop, go to Your Account from the navigation at the top of any page, and then select the option to Change your Charity. Or, from your mobile browser, select Change your Charity from the options at the bottom of the page. Select Ostomy Association of the Houston Area as your charity.

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? Changing Your Email Address?

Please make sure we have your current contact information so we can reach you by email, U.S. mail, or phone. Send updates to Lorette Bauarschi at lorette@bauarschilaw.com.

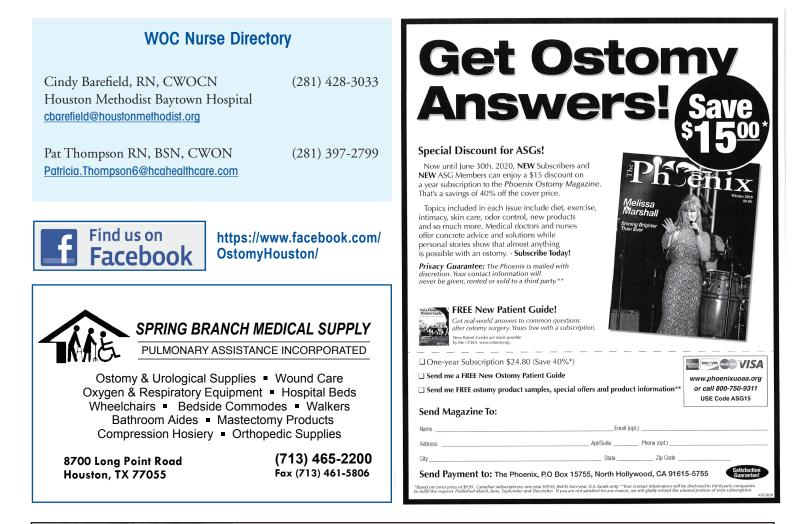
For Anniversary Gifts, Memorial Donations, Mailing Changes, or Sponsorships, please send all correspondence to:

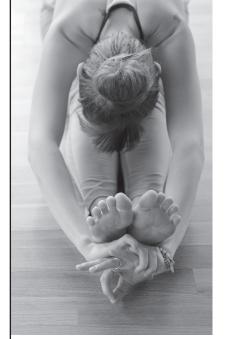
Ostomy Association of the Houston Area Attn: Mike McGinity, Treasurer P. O. Box 25164 Houston, TX 77265-5164

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



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





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†Global User Evaluation. Data on file, Hollister Incorporated. The Hollister logo, CeraPlus, and "Healthy skin. Positive outcomes." are trademarks of Hollister Incorporated. ©2018 Hollister Incorporated.



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Newsletter Advertising: Please contact the President or Treasurer for advertising opportunities.

Membership Application			
Membership in the Ostomy Association of the Houston Area requires one easy payment. Please complete 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	e the following form and mail as Date:		
Name: Phone:			
Street Address:			
City: State: ZIP: E-mail: (required)			
Surgery Date: Birth Date: Sex: □ Male □ Female	□ Other		
Reason for surgery Crohn's Ulcerative Colitis Cancer Birth Defects Other			
In additional to English, I also speak the following language(s). 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□Ileostomy□Continent Urostomy□Spouse/Family Member□Urinary Diversion□Pull-Through□Physician□Other:□J-Pouch□Nurse	Membership benefits include: 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 Sugar Land Group Woodlands Pediatric Group			
□ I would like to become a member but cannot pay dues at this time. (This will be kept confident	tial.)		
I learned about the Ostomy Association from WOC Nurse Physician Newsletter Surgical Shop Website Other:			
I am interested in volunteering. \Box Yes \Box No			
I have enclosed an additional \$ as a donation to support the association's mission of he	elping ostomates.		



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