



July 2022

Ostomy Association of the Houston Area

AFFILIATED SUPPORT GROUP

"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.

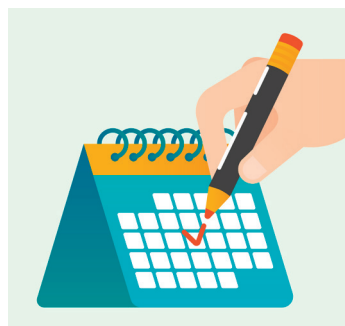
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www.ostomyhouston.org

VIRTUAL VISITOR TRAINING: VISITING SKILLS

Saturday, July 23, 2022
10 a.m.–Noon

Our Visitor Training program will be virtual this year and is planned for Saturday, July 23, 2022! We hope everyone will be able to join us.

After our program has covered basic visiting policies and procedures, the anatomy of an ostomy or diversion and the psychological and social issues, we discuss overall visiting skills.



The purpose of this segment is to review guidelines for a successful hospital visit and a successful telephone visit, stress the importance of active listening and review important follow up activities of a visit.

We often engage in role playing among certified visitors to demonstrate how to effectively handle a visit. Please join us for this important program.

RSVP to Kathleen.duplessis@outlook.com

The Heat Is On! Hydrate with an Ostomy

By Ellyn Mantell (courtesy of UOAA, July 2020)

While walking this morning it occurred to me that for many Ostomates, the heat is very challenging. Ileostomates, in particular, are prone to dehydration because our stoma is always productive. In Mother Nature's inimitable creation, the colon, or large bowel, is responsible for absorbing fluids and allowing them to be reabsorbed into the body. Since ileostomates either no longer have a colon or it is no longer being used, the precious fluids are flushed from the body through the stoma. Hence the rapid filling and refilling of the pouch, which can be worse in the heat.

Naturally, drinking water is advised. UOAA's new ostomy nutrition guide recommends you "Make a habit of drinking water throughout the day. At the same time, limit or avoid beverages with added sugars and artificial colors and sweeteners." Many of us may have difficulty drinking enough to support our anatomy, so we need to be mindful of symptoms that we are lacking the hydration/dehydration balance.

Some symptoms of dehydration include headache, fatigue, dark or decreased urine, lack of concentration, dry mouth, feeling disoriented, shortness of breath, dry skin, stomach cramps.

(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.

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.

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News from the OAHA Board

July in Houston is always hot and humid so please, take extra care and stay hydrated!! Check out the article about staying hydrated in our newsletter.

No Central Group Monthly Meeting in July. We have our Virtual Ostomy Visitor Training scheduled for Saturday, July 23, 2022, beginning at 10 a.m. It will last a little over 2 hours. If you'd like to join us and you have not signed up yet, email Kathleen Duplessis your name and phone number—kathleen.duplessis@outlook.com. Hope to see you then!

The United Ostomy Associations of America has a newly released "Eating with an Ostomy Guide". You can download the guide from their website here: Diet & Nutrition Guide. You will also be able to download an 'Emergency Blockage Card', a 'Food Reference Chart' and a 'Food Journal'. These are offered in English and Spanish!

The OAHA Board

Northwest Group News

The Northwest Group met on Wednesday, June 15th, and welcomed Physical Therapist Brock Pennywell from HCA Northwest Hospital. Mr. Pennywell has over 30 years of experience in numerous modalities. He presented some basics regarding ostomy creation, hernias and physical therapy responses and options. He took time to answer a variety of therapy questions.

We welcome the new Northwest Group facilitator Mary Kinsey who will be taking over the group in July. Ms. Kinsey works for Memorial Hermann and brings extensive knowledge and skills to our group. Welcome Mary!

Billy Locke
337-515-6354

HOPE—TCH Woodlands, Pediatric Group News

Due to Summer schedules of many of the teen members, the group will reconvene for virtual meetings in September. In the meantime, the group members will continue to reach out to new ostomy patients on an individual basis and will be available to support those needing additional supplies or troubleshooting.

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

Central Group News

Central Group met early on June 13th and had five attendees to hear nurse Ama Acheampong's excellent presentation on Diet and Exercise. Ama was very engaging and we had a great discussion on how different ostomates react to different foods. Congratulations Ama on your recent certification, and we look forward to your continued involvement with the OAHA.

Central Group will not be meeting in July because of the virtual Visitor Training on July 23rd. Hope to see you there!

Kathleen Duplessis, President, OAHA,
[Kathleen.duplessis@outlook.com](mailto:kathleen.duplessis@outlook.com) or 713-299-3180

Sugar Land Group News

Our meeting started with a presentation from Roxanne Warren with Hollister. The presentations included slide shows and videos about peri-ostomal skin myths, skin care routines, and stomal accessories.

Roxanne presented information on myths related to ostomies, including issues with fit, product material, and output that can influence wear time and skin effects. She educated the group on role ceramide plays in skin health and inclusion of ceramide to the Hollister product line, CeraPlus. Skin health is just as important as a bag that fits for persons with an ostomy.

Open Forum

Discussion included skin routines and various skin cleaning and barrier products.

Joan shared that the votes are in and all three positions were voted in for another 3 years on the OAHA board. Reminder of the upcoming Virtual Visitor Training in July, please submit your interest to Joan and she will forward your information to the OAHA board. Congratulations to Cindy Barefield, BSN, RN-BC, CWOCN, for the 2022 WOC Nurse of the Year for the UOAA! Reminded group that Houston will be the hosting city for the 2023 UOAA Annual Convention.

Joan shared that we will continue meeting virtually until further notice but that once we can meet in-person we will continue the hybrid of Online and In-Person format. Joan announced we have a new nurse navigator who will be joining Houston Methodist Sugar Land, Jennifer Cerda, MSN, RN, OCN, starting on June 20th.

Our next meeting will be on Thursday, July 21, 2022 at 6:00 p.m., virtually, our topic is still pending verification from the speaker.

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

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

Baytown Group News

Baytown Ostomy Support Group met June 13th which was re-scheduled from June 20th to avoid possible conflicts with family and friends who may be celebrating with the Juneteenth Holiday on the following Monday. It turned out to be a great evening with 10 ostomates, family and friends in attendance.

Thanks to Irma Sessums who has connections to various ostomy support groups around the country and we were able to share a link to Ostomy Academy. This link came from the North Sound Ostomy Group website. North Sound serves the south Skagit, Snohomish, and North King counties in Washington State. "Leaks Tweaks and Peaks" was hosted by Brenda Elsagher (UOAA Director of ASG Affairs) and Steve Vandevender (Director at Large) who will begin hosting the Ostomy Academy sessions. Josh Nelson, a young air force pilot who battled Crohn's and IBD before having an ileostomy shared his inspirational ostomy journey. (https://youtu.be/djcwC7Sy_0c)

Cindy shared the top innovations in the ostomy world from the recent WOCNext Conference. This led into a group discussion on how everyone was getting along. A young man with a urostomy shared a milestone in his life. He recently added a grandson to his family— he remembers the day that his surgeon talked to him about why he offered him the procedure that he did for his bladder cancer. He said clearly this surgery is not for your son— this is for your grandson. What a great day to see that come true! We are so happy for you Greg!!!

At some point the conversation landed on what items are carried with each ostomate. What's in your to-go bag? Contents ranged from a change of clothes to just an elastic barrier strip in the pocket to reinforce a possible leak. Perhaps this would be a good topic for next month. What does being prepared look like to you?

I hope you will make time to join us in July. Our meeting is scheduled for Monday, July 18 at 6:00 p.m. in the Community Resource Credit Union Meeting Room of Plaza II of the Houston Methodist Baytown Hospital. I hope to see you there!

Cindy Barefield, BSN, RN-BC, CWOCN
281-428-3033, cbarefield@houstonmethodist.org



The Heat Is On! Hydrate with an Ostomy

(continued from page 1)

Additionally, leg cramps, loss of appetite, drowsiness, tingling in fingertips and muscle weakness are all concomitant to dehydration.

Learning to live with the chronic dehydration possibility presented to ostomates is certainly attainable. For me, since I do not have a high blood pressure issue which might preclude adding salt, it means adding it frequently at meals. It is strange to servers at restaurants when I ask for the salt shaker, and many have asked if I mean the pepper shaker? We have become a salt-resistant society. But there are those of us who need it for our fluid balance. Additionally, I have a handful of a salty snack before bed, such as pretzels, since nighttime muscle cramps can be very painful and cause sleep deprivation. I keep a bottle of tonic water in the refrigerator, as well as a jar of pickles for those times when nothing else works. For muscle cramps I recommend an over the counter foam moisture. The manufacturers recommend using it prophylactically at night, but I have found it usually very fast-acting when I have foot or leg cramps, so I apply as needed.

Many Ostomates swear by sports drinks like Gatorade, but truthfully, although I have a bottle in the refrigerator at all times in case of fever, I find it difficult to drink. However, if presented with the option of drinking it or winding up in the Emergency Room for fluids, I will imbibe gladly! It's recommended you dilute sports drinks to reduce the sugar content as well. At some of our Support Group meetings I have heard of many different electrolyte balancing drinks and powders, so you may find one that works for you.

UOAA recommends you drink 8–10, eight-ounce glasses of water/ fluid daily. If you have a urostomy this also helps prevent UTIs and keeps urine diluted. Concentrated urine also can cause odor.

It has been recommended that Ostomates drink more than simply water, since it flushes through the system and little gets absorbed before it exits through our pouch. Drink with meals, since food slows down the transport of fluids. Bring fluids with you when you are out and about, since being busy may cause us to forget the responsibility we have to stay hydrated. Lastly, in addition to feeling awful when we are dehydrated, being in that state puts a great deal of pressure on our kidneys, and can lead to kidney failure and lightheadedness, which can lead to falling.

Although this sounds ominous for summer fun, being mindful and smart will help us to relax and enjoy ourselves...after all, with the Covid experience, we have learned to grab the good and be grateful we are as healthy as we are!

Ellyn Mantell is a UOAA advocate and Affiliated Support Group leader from New Jersey. You can follow her personal blog at <https://morethanmyostomy.com/>.

Patrick McKinney's Story: Leading By Living

(Courtesy of UOAA, July 2021)

Photo Credit: Dave Camara/Camara Photography

By Ed Pfueller, UOAA Communications & Outreach Manager

If you're looking for Patrick McKinney you'll likely find him outdoors. Depending on the season, McKinney, 54, of New Market, Maryland, can be found speeding down a ski slope, powering up a hill on his bike, tending to horses, or photographing his daughters playing sports.

That wasn't always the case. In 1984, as a 17-year-old, while donating at a high school blood drive, he was found to be anemic. The formerly active teen had been experiencing incontinence with blood loss for 18-24 months and was afraid to tell anyone. After confiding in his mother and seeking a diagnosis, a colonoscopy revealed ulcerative colitis. By his mid-twenties he found himself hospitalized several times after his body stopped responding to conventional steroid-based therapies. In 1993 he had the first of five surgeries that over the years eventually led to a temporary ostomy and a j-pouch. He was plagued by stricture problems and other issues with the j-pouch. "With the j-pouch I was still going to the bathroom 15-20 times a day when it was bad," McKinney remembers. When another surgery was required in 2004 because his j-pouch perforated leaving him septic, his doctor at the Cleveland Clinic prepared him for the fact that depending on how it went, McKinney could wake up with a permanent ileostomy.

Indeed that was what happened and he experienced the struggles so many new ostomates have while trying to adjust both mentally and physically. McKinney now says, "Getting an ostomy was the best thing that ever happened to me, I got my life back."

McKinney credits reading Rolf Bernirschke's book *Alive & Kicking* for encouraging him to not be held back by his ostomy. "His book got my life back on a normal track. I started being an advocate and lived life again," McKinney recalls.

McKinney wrote to Rolf and was honored to receive a Great Comebacks Eastern Region Award in 2008, which included the chance to meet the inspiring former NFL Man of the Year. Since then he has embraced taking part in sports he had never even tried before having ostomy surgery.

McKinney's first major post-surgery athletic challenge was competing in a half-marathon in Sonoma, California in 2009. The success of it inspired him to try other competitive sports. A family ski trip to Colorado piqued his interest in alpine ski racing. After entering an amateur event in 2014, he was surprised to learn his time qualified for nationals in his age group. After that he was hooked on "running gates." McKinney has been alpine racing ever since and is a member of NASTAR's Team Zardoz and the United

Ski And Snowboard Association (USSA) Mid-Atlantic Masters Ski Racing Association and trains at Montage Mountain in Scranton, PA.



During the rest of the year, McKinney can most often be found on his bicycle touring the rolling hills of rural Maryland. As a member of the Frederick (Maryland) Pedalers Bicycle Club he rides over 3000 miles per year including events like the Tour de Frederick and the Civil War Century.

"It's like being a kid again, wind blowing in your hair takes you back to your teenage years," he says. For those hesitant to try riding again McKinney advises "Being prepared helps to put your mind at ease." "Have a plan and know where the bathrooms are at local parks, I empty right before to go out. The back pocket on a cycling jersey is perfect for bringing extra supplies and wipes. My ileostomy tends to not have much output when I'm being active."

In 2019 McKinney heard that UOAA's National Conference was coming to Philadelphia, PA and welcomed the opportunity to see Rolf again and check out the unique event. Talking to other ostomates at the conference inspired him to do more with UOAA. "It helped me realize this is a chance to see what I can do, and that it is the right time to get more involved with the Frederick Area Ostomy Support Group." McKinney has been an active member and is now the group's President, supporting their activities even as in-person meetings were suspended this past year. In just the past few years he has offered his perspective as an ostomate to nursing students at a local community college and as an ostomy patient visitor. In support of Ostomy Awareness Day, he helped to procure proclamations from local government and organized a walk for the Run for Resilience Ostomy 5k, a major fundraiser for the programs and services of UOAA.

"Getting an ostomy was the best thing that ever happened to me, I got my life back."

"The biggest thing is to provide some hope. Almost everyone is devastated and so unsure about how to live through this experience," McKinney says. On a national level, McKinney is now a member of the United Ostomy Associations of America Education Committee.

"I try to lead through living my best life. Sharing what I can do, but also keeping in mind to listen to your body. Get out there and walk, or ride on a bike. For most, an ostomy will not impact that, I try to be encouraging and positive."

His advice for other ostomates looking to get active? "Your only limitation is your mind. If your doc says you are healthy enough do it, hydrate, hydrate, and always be prepared."

Central Group

Date: No Monthly Meeting
Please join us for Visitor Training on July 23, 2022
Contact: Denise Parsons 713-824-8841 rockynme2@gmail.com

Baytown Group

Date: Monday, July 18, 2022
Time: 6:00 p.m.
Place: In-Person Meeting
Community Resource Credit Union (CRCU)
 Community room. Avoid the front of the hospital (Garth entrance). The CRCU Meeting Room is located just inside the door of Plaza 2 on the back side of Houston Methodist Baytown Hospital. Park behind the hospital (exit off of Baker Rd.) (Contact group leader for more information.)
Program: Roundtable
Contact: Cindy Barefield, CWOCN, 281-428-3033

Northwest Group

Date: Wednesday, July 20, 2022
Time: 7:00 p.m.
Place: Virtual Meeting (Information is provided in the email of your July OAHA Newsletter.)
Program: Q&A and Open Forum
Contact: Billy Locke 337-515-6354

Sugar Land Group

Date: Thursday, July 21, 2022
Time: 6:00 p.m.
Place: Virtual Webex Meeting (Information is provided in the email of your July OAHA Newsletter.)
Program: TBD
Contact: Joan Burnham, MSN, RN, OCN, RN-BC, Oncology Nurse Navigator at 281-274-0188 or jmburnham@houstonmethodist.org

Woodlands Pediatric Group

Date: Meetings will resume in September.
Time: Sundays at 2:00 p.m.
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**

WOC Nurse Directory

Cindy Barefield, RN, CWOCN (281) 428-3033
Houston Methodist Baytown Hospital
cbarefield@houstonmethodist.org

Pat Thompson RN, BSN, CWON (281) 397-2799
Patricia.Thompson6@hcahealthcare.com



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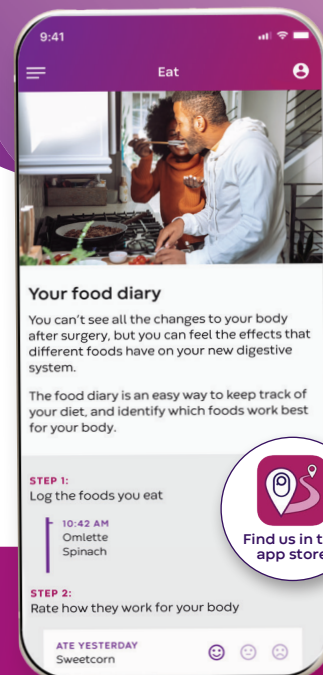
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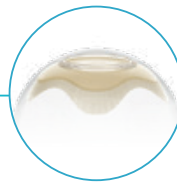


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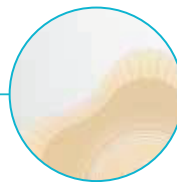
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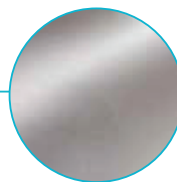
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Membership in the Ostomy Association of the Houston Area requires one easy payment. Please complete the following form and mail as directed with payment as shown.

Dues of **\$25.00 per year** are payable to:

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: **(required)** _____

Surgery Date: _____ Birth Date: _____ Sex: ☐ Male ☐ Female ☐ Other _____

Reason for surgery ☐ Crohn's ☐ Ulcerative Colitis ☐ Cancer ☐ Birth Defects ☐ Other _____

In addition to English, I also speak the following language(s). Foreign language spoken: _____

Why do we ask this? We have a patient visiting program and we are occasionally contacted by ostomates who are not fluent in English and we look to our membership to assist with communication.

Procedure or Relationship:

To help us complete our records, please answer the following.

Check all that apply.

- | | | |
|--|--|---|
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| <input type="checkbox"/> Ileostomy | <input type="checkbox"/> Continent Urostomy | <input type="checkbox"/> Spouse/Family Member |
| <input type="checkbox"/> Urinary Diversion | <input type="checkbox"/> Pull-Through | <input type="checkbox"/> Physician |
| <input type="checkbox"/> Other: _____ | <input type="checkbox"/> J-Pouch | <input type="checkbox"/> Nurse |

*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 Sugar Land Group Woodlands Pediatric 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.



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