

#### AFFILIATED SUPPORT GROUP

"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

#### **Managing Odors**

by Joan Burnham, MSN, RN, OCN, RN-BC, Oncology Nurse Navigator, Sugar Land Group Leader

It is not uncommon for ostomates to think that everyone can smell the odor that their bags may contain. It really is a matter of "out of sight, out of mind." As an ostomate, your poop is potentially always visible and we may associate sight with odor. Truthfully, unless your appliance or bag is leaking, there is no odor. Your appliance and bag are not only waterproof but theoretically, odor-proof. Yet, the thought persists that there is a smell emanating from our devices. What to do?

Rule number ONE—empty your pouch more often when it is 1/3 to ½ full. You will find that there is a best level to empty your bag and that knowledge comes with time and experience. What works for one person may not be best for someone else. The type of stoma you have will also determine frequency of needed emptying. Ileostomies will need to be emptied more often as there is more output versus a colostomy which the output is less and more firm. Urostomy output is dependent on how much fluid has been drunk and what medications a person is using (diuretics increase urine).

Rule Number TWO—Avoid certain foods and beverages. What gave you gas and increased odor before your ostomy surgery, still stands true with an ostomy. Documenting your diet and output will help you find out what does and does not work for you. This is also known as logging or journaling. You can be as detailed as you like listing food, amounts, and time eaten along with time of stool with amount, color, odor, and consistency. In a simple journal you may just list foods eaten and how much poop was produced.

(continued on page 3)

#### **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.

### Excellence in Nursing Awards: Cindy Barefield, Pat Thompson, and Sarah Arriaga

There are jobs, and then there are callings. Some people are just born with the gift of caregiving, and through their gifts, they make our city a better place to live.

Cindy Barefield, Pat Thompson, and Sarah Arriaga, were recently named 2020 Excellence in Nursing Award Winners—Bronze Medalists. Cindy, Pat, and Sarah were nominated by their peers for their dedication to excellence. The Good Samaritan Foundation received 533 nominations from many different hospitals, clinics, colleges and universities. The Excellence in Nursing Awards honor registered nurses and educators who are nominated by their peers and selected by a distinguished Awards Selection Committee. These nurses demonstrate a passion for the nursing profession and exemplify excellence in teaching, mentoring, leadership and service.

The Ostomy Association of the Houston Area is delighted to congratulate Cindy, Pat, and Sarah for this prestigious award—we are so proud of you all and so grateful for everything you do for the ostomy community!! Look for a special article honoring Cindy, Pat, and Sarah in our September newsletter—stay tuned!

Congratulations to Pat, Cindy, and Sarah!

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**

We still are not meeting in person but many of us are certainly enjoying monthly virtual meetings. The July WebEx meeting was hosted by Joan Burnham, MSN, RN, OCN, RN-BC, Oncology Nurse Navigator, Houston Methodist Sugar Land Hospital. We learned some great tips on eliminating and controlling odors and even had a YouTube viewing from one of my favorites, Amber from Ostomy Diaries. Thank you, Joan, for a most enjoyable virtual meeting! Joan and her staff will be hosting the next virtual meeting on Thursday, August 20, 2020 at 6 pm and we will hear from Sarah Arriaga, BSN, RN, CWOCN who will speak on Ostomy Changes—What to Know. Please let me or one of the board members know if you would like access to the August 20th virtual meeting.

We are so proud of Cindy Barefield, Pat Thompson, and Sarah Arriaga for being Bronze Medalist award winners in the **2020 EXCELLENCE IN NURSING AWARDS!** Thank you for all you do for the ostomy community—we greatly appreciate all of you! Patti Suler will be highlighting Cindy, Pat, and Sarah in our September Newsletter.

Mike McGinity and I regret to report that due to the continued uncertainty with COVID-19, UOAA has made the decision to cancel their 2021 National Conference which was to be held in Houston. Mike and I were on the conference planning committee. The UOAA will revisit the situation some time next year to determine if they will hold a 2022 conference.

As we are all pretty much home bound, now is the perfect time to try that ostomy product you have been thinking about. That way, if it works—great but if it doesn't work you won't be left in an awkward situation with a leak or worse! So, call Coloplast, Convatec, Hollister or any of the other companies and talk to their support staff and ask for samples of that pouching system or product you have been considering!

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

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.ostomy.org or 800-826-0826

#### **Northwest Group News**

The Northwest Group will not be having a August meeting. The Ostomy Association of the Houston Area groups are currently working together to consolidate our monthly online meetings to better leverage our limited volunteer resources.

Billy Locke, 337-515-6354

#### **Baytown Group News**

Baytown Ostomy Support Group will not meet in August as we are still observing social distancing requirements. We plan to stay in touch via email.

You are welcome to join the Sugar Land Group Virtual Meeting on August 20.

Best regards,

Cindy Barefield, RN, CWOCN 281-428-3033

#### **Sugar Land Group News**

The Houston Methodist Sugar Land Hospital Ostomy Support Group sponsored the monthly meeting virtually. Joan Burnham MSN RN OCN RN-BC presented a slide show and information on managing odor and appearance. Joan highlighted Amber Wallace a vlogger of OstomyDiaries.com, who has a wide variety of videos to help the new or old ostomate with a very upbeat vibe. Participants had an opportunity to share their knowledge and tricks and ask questions. Please see the article in this month's newsletter for more information.

Our next meeting is August 20, 2020, at 6-7 PM and will also be a WebEx. Our speaker will be Sarah Arriaga, BSN, RN, CWOCN who will speak on Ostomy Changes—What to Know. For more information, please contact Joan Burnham.

**Joan Burnham, MSN, RN, OCN, RN-BC**, Oncology Nurse Navigator at <a href="mailto:jmburnham@houstonmethodist.org">jmburnham@houstonmethodist.org</a> or 281-274-0188

#### **HOPE—TCH Woodlands, Pediatric Group News**

The HOPE group will not be meeting in August. You are welcome to join the Sugar Land Group Virtual Meeting on August 20.

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

#### Managing Odors (continued from page 1)

In general foods that are high in soluble fiber and/or sugars are more likely to cause gas, some with a potent odor. Another odor producer is fish, and it can be overwhelming. If this is something you experience, it may be one of those foods that you reserve for eating when you don't have anywhere to go the next day. Some foods may actually decrease an odor, like buttermilk, cranberry juice, parsley, and yogurt.

Be careful about swallowing air, which can increase gas and bloating of your bag. Common ways to swallow air include chewing gum, drinking through straws, drinking carbonated beverages, eating and drinking too fast, and smoking. It is important to note that some medications can change the amount and consistency of your output, as well as the color and odor.

Rule Number THREE—Use a filter in or on your pouch. Many pouches come with an integrated filter but if no filter is present you can add a filter. Some filters contain activated charcoal which will neutralize some odors. Have you ever seen the small adhesive patches in your box of bags?—These are filter covers and you can use these to control release of gas from your pouch. You would also use these when taking a shower or bath or if going swimming to prevent water from entering the filter. Just remember to remove the filter cover once you are ready for some gas to leave your bag. Some people prefer to leave the filter open at night so that gas does not fill the bag and lead to a "pop off" event!

Rule Number FOUR—Use odor eliminators, which come in the form of tablets, drops, and sprays. Appliance deodorizers are substances that can be placed inside your pouch. Many ostomy supply companies have their own brand, such as m9®, Bansih II®, and Securi-T®. People with ileostomies may also use OstoGel® packets that turn liquid output to a gel and eliminate odor. Some people use things like Tic-Tacs® or mouthwash in the bottom of their bags to manage odor when emptying. Please be careful as those substances can irritate the stoma if it comes in direct contact with the stoma.

Room deodorizers are an option but it may only mask the smell rather than eliminate odor. The Hollister m9 can be used both in the bag and as a room deodorizer. Products that eliminate odor are usually potent and should be used sparingly, such as Ozium®, SolidAire® or X-O Plus®. Some people also apply the deodorant or a perfume spray to the outside of their bag to manage odor.

An internal deodorant is a substance that is a chewable tablet and helps get rid of odor from both gas and stool. Devrom® (bismuth subgallate) is one option and is especially active against sulfur based smells, like eggs.

**Rule Number FIVE**—Find the right ostomy bag for you. This is the last of the rules and will need your active participation. Initially, all patients get what appliances are in stock at the facility where they have their stoma created surgically. While the item you received may meet the need of a new stoma, it may not be the best for you on a long term basis. You need to consider what type of



stoma you have, the volume of your output and the lifestyle you have, then look for a bag that meets those needs.

If you have issues with emptying a bag cleanly and odor is always present due to small amount of stool stuck to the outside of your bag, then a disposable two-piece may be better for you. A two piece with a disposable bag requires you to remove the bag and trash it, then apply a new bag to the wafer. A simple wipe around the stoma before putting on a new bag is much easier for some people. If you are not sure what you want, then call companies for samples and try them out. "Nothing Ventured, Nothing Gained" is a wonderful quote to start you on your journey to a better life with a better bag.

It is also good to know what accessories may help keep your bag firmly attached and durable for at least 3-5 days. Having to constantly change your wafer leads to raw and tender skin around your stoma. Skin barriers, powders, sprays, and rings can help form a good seal that both protects your skin and contains odors.

Also remember the resources available to you through the local Ostomy Association and community support groups.

### Kindred Box Helps People in America Who Need Ostomy Supplies.

Kindred Box is a 501(c)(3) organization dedicated to improving the lives of people with ostomies. Since 2017, they have been collecting donations for programs that provide free ostomy supplies to U.S. military families and for disaster relief assistance, including national emergencies. They also maintain an online charity store which offers low-cost options solely for the people in their program who are uninsured or underinsured.

"Many are fortunate to have excess supplies, yet others don't have any. Making this connection is very important to our mission."

— Christine Kim, founder of Kindred Box

When the charity first began, they were assisting only a few dozen people but two years later that number grew to over 200 people — just by word of mouth. In 2019, over 8,000 donated items were distributed nationally. And so far this year, that number has already doubled.

You may be surprised to hear that some ostomates in America do not have supplies. And you may be thinking: Why is that? And what do they use? Christine has spoken to hundreds of people, including Jessica from New York who was waiting on her insurance to approve an order from a supplier, and down to only one pouch. If help didn't come fast, Jessica said that baggies and tape was how she'd get by. She couldn't afford to pay retail and said depression was hitting her hard.

Waiting weeks, even months for insurance approval is one reason for a short-term need, but there are other reasons which can be long-term or lifelong.

- Some return home from the hospital with the \*shocking\* news that ostomy supplies are not covered by their insurance policy.
- Some who have health insurance say their deductible for ostomy supplies is very high or the quantity allowed is very low.
- Some do not have health insurance or lose their coverage due to job
  loss
- Some endure a natural disaster and lose everything, including their supplies.

Christina Mullins contacted Kindred Box after her son Zachary had ileostomy surgery because of Crohn's disease. They'd been using samples from the manufacturers but when those ran out, she couldn't afford to pay out-of-pocket for more supplies. Not only were they drowning in medical debt but when Christina's husband lost his job, the family lost their insurance. Thankfully, she came across Kindred Box on Facebook and reached out for help. About a week later a 'Kindred Box' arrived and they were relieved.

"My son was down to his last bag and we so needed these supplies for him. Thank you so much. One less stress to worry about."

—Christina Mullins

Their founder credits the kindness of many as the reason Kindred Box has grown year after year. There's even a page on their site dedicated to supporters with thank you letters and notes of appreciation. Christine said, "We would simply not exist today if it weren't for each and every generous donation to help our community."

Kindred Box gives ostomates a new lease on life. With access to affordable supplies there's more freedom, so they can go to work, take care of their kids, and simply get back to living. More importantly, they genuinely know that someone cares.

To learn more about Kindred Box, donate supplies, or request assistance, please visit



Christine, Rita, Gwen, and Charlotte
Team at Kindred Box
info@kindredbox.org
kindredbox.org

#### Rice 360° Institute for Global Health Creates Low-Cost, Reusable Ostomy System

Shravya Kakulamarri, Global Health Fellow, Rice 360° Institute for Global Health, Rice University

The Rice 360° Institute for Global Health at Rice University has been working to develop a low-cost, reusable ostomy pouch. It is designed to be low-cost, comfortable, and durable for everyday use, while maintaining its core functions of leakage prevention and odor reduction. The Rice 360° team has had the pleasure of presenting at The Ostomy Association of the Houston Area meetings in the past and has received very valuable feedback from this community.

There is an urgent need for inexpensive ostomy supplies designed for low-resource settings. In these settings, patients who cannot afford the high cost associated with commercial ostomy supplies sometimes resort to unconventional waste collection systems made out of plastic, lids of jars, cloth, and other repurposed items. These improvised systems can increase risk of skin abrasions and lesions around the stoma.

The Rice 360° novel ostomy system collects stomal effluent through a reusable ostomy pouch with a lifetime of up to two years. The reusable pouch uses any disposable plastic bag, such as Ziploc bags, as disposable inner liners that can be changed as needed. A silicone adhesive wafer, which is used to attach the system to the abdomen, can be washed and sanitized between each use while still maintaining its adhesive capacity; it lasts up to two weeks. The only recurring costs to the patient are the wafers and disposable inner liners. This system is only a fraction of the yearly cost of commercial ostomy pouches.

We are currently in the process of refining the design and beginning usability and comfort trials with non-ostomates. Upon successful completion of these trials, we anticipate enrolling ostomy patients in early fall. We are eager to make more progress on the design and bring the device closer to the stage of commercialization.

If you are interested in getting involved with the project or would like to stay updated with our progress, please email us at <a href="mailto:colostomates@rice.edu">colostomates@rice.edu</a>.

#### **Central Group**

Monthly: Third Monday of the month

**Date:** No meeting in August—Join the Sugar Land Group

Virtual Meeting on August 20.

**Contact:** Denise Parsons 713-824-8841 rockynme2@gmail.com

#### **Baytown Group**

Monthly: Second Monday of the month

**Date:** No meeting in August—Join the Sugar Land Group

Virtual meeting on August 20.

Contact: Cindy Barefield, CWOCN, 281-428-3033

#### **Northwest Group**

**Monthly:** Third Wednesday of the month

**Date:** No meeting in August—Join the Sugar Land Group

Zoom Meeting on August 20.

**Contact:** Billy Locke 337-515-6354

#### **Sugar Land Group**

**Monthly:** Third Thursday of the month

Date: August 20, 2020

**Time**: 6:00 p.m.

All are welcome, contact your group leader for

more info.

Place: VIRTUAL WEBEX MEETING (Learn more on

page 2 or contact Joan Burnham for login info.)

Program: Speaker: Sarah Arriaga, BSN, RN, CWOCN who

will speak on Ostomy Changes-What to Know

**Contact:** Joan Burnham, MSN RN OCN, Oncology Nurse

Navigator, 281-274-0188

#### **Woodlands Pediatric Group**

Monthly: Second Sunday of the Month

**Date:** No meeting in August—Join the Sugar Land Group

Virtual Meeting on August 20.

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.)

#### **WOC Nurse Directory**

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

Pat Thompson RN, BSN, CWON Patricia. Thompson 6@hcahealthcare.com

(281) 397-2799



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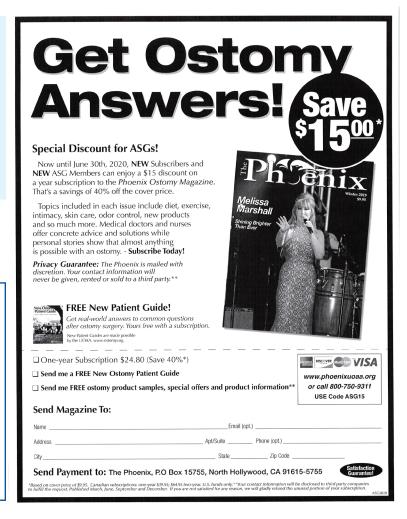


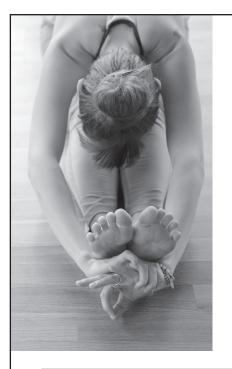
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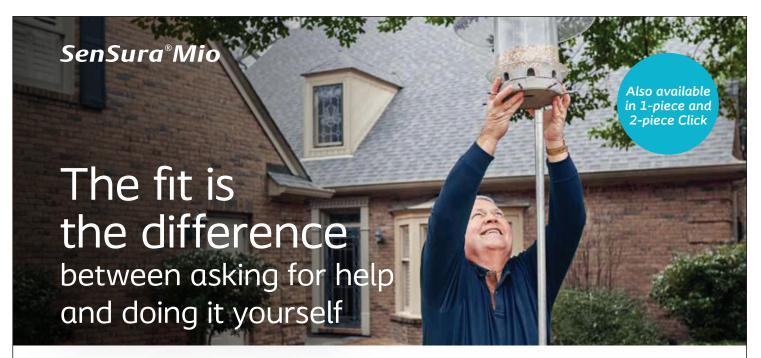
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