UOASL 2020 MEETING SCHEDULE

www.uoaastl.org

Stay tuned to the website and Facebook page for updates

July 6 St. Luke's – Show and Tell - Room 4 & 5

July 20-25 Youth Rally Virtual on Zoom .

August 3 St. Luke's - Youth Rally Follow Up –Room 4 & 5

*September 14 St. Luke's - Summer Wrap-up. Dinner provided by UOASL - WOCN Panel - Room 4, 5, & 6

**October 5 Christian Hospital - Detrick Building West of hospital 2nd floor WOCN office

November 2 Leonard Naeger Memorial Lectureship - Drugs & Your Ostomy - St. Luke's Hospital Room 4 &5

December 7 Annual Banquet (Starts at 6:30PM) Syberg's Restaurant, Dorsett Rd

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Any articles welcome for consideration:
personal experiences, health, obituaries, tested tips, etc.

Publication Deadline August 25, 2020

Send articles to: Mary Beth Akers
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St. Charles, MO 63303
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LIVE & LEARN by Email

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The National UOAA is on both!
To find us on Facebook, go to Facebook.com/UOAA Inc.
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or while logged in, search for @UOAA.
You can find our social blog at blog.ostomy.org.

Affiliated With United Ostomy Associations of America, Inc.

LIVE AND LEARN

Summer 2020

President's Message

To All Members and Friends of UOASL,

No one could have ever imagined where we find ourselves today. Fortunately, through the wonders of the internet and Zoom, some of us have been able to find connection through our monthly meetings in May and June. I am hopeful that we can gather in person in July but still don't know. I had the opportunity to Zoom with the DuPage chapter up near Chicago this week. One statement their president, Bret Cromer, had heard was how grateful those who weren't able to come to the meetings on a regular basis were finally able to "attend" and see everyone. He was asked if he would continue to broadcast the meetings virtually once we are able to gather again. I told him that was a wonderful idea so we will be doing it as well. I know some of you don't have the internet access and have been missing the in person meeting immensely, but looking at the positive, some have now been able to partake.

We also had our quarterly board meeting in March by zoom and will do the same this month. We decided to go ahead with the product fair raffle because people had already sent their tickets in. The plan was for me to just pull the winners and call them but that was before I started teaching using zoom and saw the opportunity to include chapter members. Congratulations to the winners, Janet Thompson who was on the call with us at the time and Norm Stimers who received his in the mail.

On a similar note, the Youth Rally will be entirely virtual this summer. Campers and counselors will still gather in their groups, listen to general sessions and have breakout groups all on the computer. And like the meetings, we look forward to having a few campers who would not have been able to travel to Rally. We know how much campers look forward to this week all year so we are going virtual this summer. I look forward to sharing how things went in our next issue in September.

Since we are not meeting and you are not able to pick up product, reach out if you are in need.

I have been contacted by Ed Carter who wanted to share an article you might be interested in. It is on the website. Uoaastl.org under support groups and ostomy resources. Financial Planning Questions

I look forward to seeing you at a meeting, whether in person or online. Please do not hesitate to reach out. 636-916-3201 marybethakers@excite.com

Mary Beth Akers, President UOASL

IT'S "ALL IN THE BAG"

Excerpt from article by Jennie David Boston University via Ostomy Association of Greater Chicago, Broward Beacon, Ft. Lauderdale, FL, and Springfield Ostomy Family Newsletter

Accidents Happen: Although advanced appliance technology has allowed ostomates the freedom to exercise, swim, and engage in other normal activities without limitations, there are nonetheless skills required in order to properly care for the ostomy. If the pouch is not properly secured on the abdomen or the wafer (the part of the pouch that sticks to the skin) has been eroded by ostomy output (i.e. not changed frequently enough), many patients experience leaks. Anatomically, the human body only has nerves that signal the need to use the bathroom in the ascending colon, therefore individuals with an ostomy do not retain the ability to know they "have to go," and similarly cannot tell if the pouch is full without actually checking it.

Accidents, whether they are in private or in public, are not only embarrassing, but also have the potential to undermine the individual's confidence in properly using ostomy supplies. This confidence is "key to [the ostomate's] understanding" of their degree of perceived control over the situation. Further, the act of emptying the pouch itself can become a negative experience due to the actualization and recognition of altered anatomy.

Betty, a 67-year-old woman with a colostomy – a procedure she described as a "mutilation" – found it so disturbing that she severely restricted her diet so that she would not have to empty the pouch.

Prepare to Succeed: Ostomies are not simply life changing, but they are life saving for those who need them. While the largest factor in predicting postsurgical body image is an ostomate's self efficacy, the importance shifts from what predicts body image to what can be done to restore it.

In order for ostomates to feel and be successful postsurgery, steps need to be implemented at every part of the process. A Wound, Ostomy and Continence Nurse (WOCN) should be able to provide new patients with reliable information regarding diet, exercise, postsurgical instructions, and warning signs that may require medical attention.

If possible, patients should be given access to see and feel the appliances before their surgeries to become familiarized. The most prepared and supported patients will be able to properly emotionally cope in as little as two to three weeks after their surgery. The average modern patient takes anywhere from six to twelve months to physically recover comfortably to life with an ostomy; this represents a significant change from the five to ten years it was estimated to take in 1965. When the patients realize the freedom an ostomy can provide, they will discover that strength, courage, determination, and spirit are all "in the bag."

2053 Via Winnipeg

One morning in September 2053 young Bobby woke to go to the bathroom. It wasn't just any morning. Today he would open the last roll of paper his parents had bought in 2020.

PLEASE NOTE

The PHOENIX magazine is the official magazine of the United Ostomy Associations of America. A portion of each subscription fee is used by UOAA to pay for the services it provides. By subscribing, in addition to getting the #1 rated ostomy magazine that is published, you are supporting the continued work UOAA provides to the ostomy community.

The 80 page Summer 2020 Issue is now available. This ostomy magazine provides answers to the many questions and challenges of living with an ostomy. It features exclusive, in-depth articles written by ostomy experts, medical professionals and ostomates that inform, educate and inspire.

Thank You! Ken Aukett, UOAA Co-Founder

VISITING SERVICES

Upon request from you, a Doctor, a Nurse, or an Enterostomal Therapist (Wound Ostomy Continence Nurse): A **VISITOR**, who has been specially trained will be sent to visit an Ostomy patient, either Pre- Op or Post-Op. The visitor will be chosen according to the patient's age, sex and type of Ostomy. There is **NO CHARGE** for this service and **WE DO NOT GIVE ANY TYPE OF MEDICAL ADVICE.** We only show the patient that his/her operation is not the end of the world, but a NEW pain free beginning to life again. Call Mary Beth at 636/916-3201.

Urolithiasis

by A. Trudeh, RN, ET

Thanks to Metro Maryland *Thrive* via Anne Arundel OA, Maryland and The Pouch

Urostomates, ileostomates and transverse colostomates have one thing in common: continuous output with a loss of fluids. If the liquid intake does not exceed the output, these ostomates may be dehydrating their bodies, making themselves prone to a condition called "urolithiasis," which refers to the presence of stones in the urinary system. These stones may be found anywhere from the kidneys to the bladder. They vary in size from mere granular deposits, called sand or gravel, to bladder stones the size of an orange. In the majority of stones, 90% are composed of calcium, with 5-8% uric acid and 1-3% cystine accounting for the rest.

Conditions which predispose to stone formation are: 1) infection, 2) periods of immobility, 3) concentrated urine, 4) abnormally high concentration of calcium in the blood, 5) heredity and 6) dehydration.

If you were to develop urolithiasis, the symptoms you might experience are: 1) low back pain and/or severe, sharp pain in the lower back radiating to the groin; 2) chills, fever; 3) difficulty or burning with urination; 4) blood in the urine; 5) nausea, vomiting and diarrhea. See your physician as soon as possible if any of the above symptoms appear.

Measures to prevent stone formation are: drink 2-3 liters (quarts) of fluid daily — preferably water and juices. Include acidic juices such as cranberry to maintain acid urine which helps prevent infection. Urinate during the night, if necessary. Exercise daily. Use caution with foods containing calcium. Since a certain level of calcium is required for good health, restrict your diet only on the advice of a physician.

FIVE REASONS WHY LIVING WITH AN OSTOMY IS AWESOME

ViaFacebook: Leah's Life, Lemons & Lemonade

Leah Nikki, entrepreneur and lifestyle blogger in Texas, Via Dupage Newsleak

I'd like to point out just a few reasons why living with an ostomy is awesome (and sometimes downright hilarious).

1) I'm still alive and symptom-free. I'm just going to say this is the most obvious reason to me. I owe my life to ileostomy surgery, and for that, I'll always be grateful. I'm in awe.

2) I never have to race to make it to the toilet. For anyone who's had "the runs" where you literally have to RUN to the bathroom. That no longer exists for me. There is literally no urgency anymore. I simply empty my ostomy bag when needed. Awesome right?

3) When my stoma "farts" it doesn't sound like a fart. Have you ever accidentally farted at the most inopportune moment and wanted to just pass out from embarrassment? Well, I have. Thanks a lot, Crohn's disease. But now with an ileostomy, my stoma noises don't actually sound like a fart. Plus, nobody else will smell anything (it's in the bag 😉) and they probably won't even know what the noise was, much less who it came from. Awesome!

4) It takes hardly any time to "go" with an ileostomy. How much time do you waste sitting on the toilet going #2? If you're a person with inflammatory bowel disease or other digestive disorder, then it's probably A LOT. With an ileostomy, that went away for me. I go into the bathroom, empty my bag, wash up, and I'm done. It literally takes me the same amount of time to empty, as it does to pee. That is awesome!

5) I don't actually have to touch yucky public toilets. Okay, so this is probably my favorite thing about living with an ostomy. You know when you walk into a public restroom and it's DISGUSTING? And what about using a port-a-potty? GROSS! Then it occurred to me, I don't actually have to touch it. I can lean over and empty into the toilet without ever sitting on the seat. How many of you can do that? Well with an ostomy, you can. It's awesome!

I hope what I've shown you that not only is this life-saving surgery but that it can change your life for the better. YOU. CAN. DO. THIS. I promise.

∗ *A grandfather was delivering his grandchildren to their home one day when a fire truck zoomed past. Sitting in the front seat of the fire truck was a Dalmatian dog. The children started discussing the dog's duties. "They use him to keep crowds back," said one child. "No," said another. "He's just for good luck." A third child brought the argument to a close. "They use the dogs," she said firmly, "to find the fire hydrants."*

ABOUT BLADDER CANCER

From Cancer Treatment Centers of America
via *Ostomy Life* newsletter, Tulsa, OK

Bladder cancer is the sixth most common cancer in the United States, with more than 80,000 new cases diagnosed each year, according to the National Cancer Institute. Men are four times more likely to be diagnosed with bladder cancer from the disease than woman. Bladder cancer is the eighth most common cause of cancer death among men.
The bladder is a hollow organ that stores urine before it is discharged from the body. Urine travels to the bladder from the kidneys through tubes called ureters and from the bladder out of the body through the urethra. The lining of the bladder, call the urothelium, is made of cells called urothelial cells. Ninety percent of bladder cancers develop in urothelial cells, a type of bladder cancer called transitional cell carcinoma (TCC).

WHO GETS BLADDER CANCER?
Bladder cancer is most often found in older adults. According to the National Cancer Institute:

- The average age of a person at the time of a bladder cancer diagnosis is 72.
- The average age of a person who dies from bladder cancer is 79.
- Bladder cancer is most frequently diagnosed in people between 65 and 74 years old.
- More than 92 percent of all new cases of bladder cancer diagnosed in people older than 55.

WHAT CAUSES BLADDER CANCER?
While the exact causes of bladder cancer are not always known, age and gender are among the most common risk factors.
Other risk factors include:

- Family history
- Inherited gene mutations or hereditary cancer syndrome
- Smoking
- Chronic bladder infections
- Long-term use of catheters

TREATING BLADDER CANCER
Surgery to remove all or part of the bladder is usually the first-line treatment for bladder cancer. Immunotherapy may also be a treatment option for some bladder cancers. The types of immunotherapy that may be recommended include:

- Checkpoint inhibitors
- Cancer vaccines

https://www.cancercenter.com/cancer-types/bladder-cancer

Coronavirus Effects on the Ostomy Community

via UOAA March 2020 E-News and UOAA Blog Post

The ostomy community is understandably very concerned about how the COVID-19 outbreak is affecting their daily lives, health, support networks, and access to ostomy supplies.

In this time of great uncertainty, UOAA recommends all individuals consult with their own primary care physicians with questions concerning their risk factor or if they exhibit any symptoms. Please follow the Centers for Disease Control (CDC) website for actual up to date information. We recognize that many people living with an ostomy or continent diversion are older people and those with chronic disease and are therefore at higher risk of developing serious illness. Please also see CDC guidelines for people at risk.

UOAA is also hearing from many Affiliated Support Groups who have prudently decided to cancel their upcoming meetings. Members should expect that their meetings will be canceled for the foreseeable future. Affiliated Support Groups are each independently run and members should contact their local leaders if they have any questions about their meetings. Community guidelines are also available from the CDC to assist leaders in deciding steps they should take to address public health concerns.

UOAA reached out to the major ostomy manufacturers to see if the outbreak is currently impacting their production or supply chain. As of March 4, 2020 none of the manufacturers reported any issues in their operations as a result of the COVID-19 outbreak. Read our previous blog post for statements from individual manufacturers on this topic. Check with your distributor to see if there are any shipping delays due to increased demand of all goods at this time.

If you develop a fever, cough and have difficulty breathing always contact your healthcare provider. They will determine if you are a candidate for a COVID-19 test. Medicare and private insurance should cover a test to see if you have coronavirus if requested from a physician. Additionally, Medicare is offering telemedicine options so people can stay home as much as possible during this crisis. Contact your private insurer to discover any additional benefits they may be offering at this time. For frequently asked questions and facts about this virus follow updates from the CDC on the latest COVID-19 guidelines.

For updates to these statements, check the blog post on the UOAA website at www.ostomy.org/coronavirus-is-not-affecting-ostomy-supply-production/

WHO WILL EAT ALL THIS FOOD?

Submitted by: Ed Tummers

Source: Metro Halifax News Reprinted from WOA's Inside/Out Oct. 2012

A few years ago, I visited a gentleman in hospital after his ostomy surgery. He was recovering very well and was excited about going home. As the hospital staff said to him: "John, you are doing great. Just keep on doing what you're doing." Two months later, I called John to invite him to our monthly meeting. His wife answered the phone and said that John had no energy and was too weak to attend. Repeated invitations got the same response. Finally, I convinced John and his wife to attend the Christmas auction and banquet. We greeted John and his wife at the door and introduced them to a few other members. Seeing all the delicious food spread out on the banquet tables immediately caught their attention. But, they asked, where was the food for the ostomates" What would John eat?

We innocently answered that John could eat whatever he wanted. What we heard next totally shocked us. John had been blending all his food since he had left the hospital. No wonder he had been too weak to attend meetings. How could this possibly have happened? This is the explanation. When John had left the hospital, he remembered them saying: "Just keep on doing what you're doing." And because he had recovered so well in hospital, they discharged him before he had moved on to solid food. So John felt that he had to keep on eating mushy food, which he hated. He was slowly starving himself. It was a delight to see John fill his plate with real food and chow down. And his wife was so pleased she no longer had to prepare a special meal for him.

Their special Christmas gift was a return to a normal life again. And that is what our ostomy support group is all about.

How Grandchildren Perceive their Grandparents *Via The Pouch*

∗ *My young grandson called the other day to wish me Happy Birthday. He asked me how old I was, and I told him, 72. My grandson was quiet for a moment, and then he asked, "Did you start at 1?"*

∗ *When my grandson, Billy and I entered our vacation cabin, we kept the lights off until we were inside to keep from attracting pesky insects. Still, a few fireflies followed us in. Noticing them before I did, Billy whispered, "It's no use Grandpa. Now the mosquitos are coming after us with flashlights."*

∗ *Children's Logic: "Give me a sentence about a public servant," said the teacher. The small boy wrote, "The fireman came down the ladder pregnant." The teacher took the lad aside to correct him. "Don't you know that pregnant means?" she asked. "Sure," said the young boy confidently. "It means carrying a child."*

UOAA Advocates Making an Impact on the Hill

By Jeanine Gleba, UOAA Advocacy Manager

The Digestive Disease National Coalition (DDNC) is an advocacy organization composed of the major national voluntary and professional societies concerned with digestive diseases. DDNC's mission is to work cooperatively to improve access to and the quality of digestive disease health care to promote the best possible medical outcome and quality of life for current and future patients. UOAA has been a member of this coalition for many years.

Each year the DDNC hosts a Spring Public Policy Forum. This year they celebrated their 30th anniversary! This special event was a two-day advocacy conference held March 1-2, 2020 that brought together patient advocates, health care providers, and organizational members the coalition. Passionate and dedicated advocates traveled from 28 states all across the country and Washington, DC. Over two days, attendees heard from multiple panels of leaders in the digestive disease community, attended a reception celebrating the coalition as well as its champions, and advocated for medical research and patient care on Capitol Hill.

UOAA had five ostomates representing UOAA and the ostomy community. We are grateful that Lacee Harper, Rena Munster, Michael Quear, Mollie Tinnin, and Lynn Wolfson joined UOAA President Susan Burns, and myself in Washington, DC. They spoke up about improving treatment for digestive diseases, shared their ostomy story and advocated for legislation such as the Removing Barriers to Colorectal Cancer Screening Act and the Safe Step Act (https://www.ostomy.org/take-action/). While mingling with attendees, we also had the pleasure of meeting a new ostomate advocate, Nancy Pederson, and a mother of a young daughter with an ostomy, Jessi Richards, who was attending as a representative for the Megacystis Microcolon Intestinal Hypoperistalsis Syndrome (MMIHS) Foundation. We hope both of them will advocate with UOAA in the future.

The greatest take-away message from honorees and guest panelists was the impact we make on the Hill. For example, it is truly because of patient advocates sharing their stories that we have seen increases in medical research funding. To give you a glimpse into my day on the Hill, I was on Team 6 with a surgeon from Nebraska and an IBD patient advocate from Connecticut. I found we were met with very positive responses by legislator staffers in the Senate and House. In many cases, the offices we visited were already co-sponsors of the different legislation pieces and this occurred on both sides of the aisle. They certainly all "got" the Safe Step Act and need for proper gluten labeling. When I followed up with my Congressional office (NJ Rep. Josh Gottheimer), they informed me that they have now signed on to the Medical Nutrition Equity Act (H.R.2501). Our visit and advocacy message resulted in a positive outcome!!!

Continued

New this year we advocated about non-medical switching as it relates to ostomy supplies. It can take patients and their medical team quite a while to find the right "fit" ostomy pouching application system. However, we are finding, for example, that insurers in some cases are restricting to using a different brand such as a generic, which do not always have the same quality or reliability. Ostomy supplies are prosthetic devices and a person's complete pouch system is customized for their unique stoma fit and individual needs. It is not okay for others to just switch that out! We urged Congress to limit out-of-pocket costs and curb current and future payer tactics proactively. UOAA will continue these advocacy efforts throughout the year. If you have experienced your supplies being switched out for non-medical reasons and it resulted in restricted access to your preferred products, or an increase in your out-of-pocket costs, or it negatively impacted your health or quality of life, submit your story to UOAA/Advocacy.

. UOAA Advocacy COVID-19 Update

By: Jeanine Gleba, Advocacy Manager

UOAA has been advocating for its ostomy community behind the scenes from the safety of our homes. In recent weeks the Coronavirus Preparedness and Response Supplemental Appropriations Act, the Families First Coronavirus Response Act, and the Coronavirus Aid, Relief, and Economic Security (CARES) Act have been signed into law. As Congress continues to work on further legislation to help our country recover from this crisis, UOAA has been supporting efforts on several fronts with its Digestive Disease National Coalition partner members to advance our positions and the potential for legislative/policy action in the context of the deadly virus COVID-19. This includes advocating for permanent and temporary reforms that remove barriers to quality, accessible, and affordable care for patients with chronic health conditions, and in support of health care providers on the front lines.

One such push includes joining over 200 patient and provider organizations urging the administration to redouble its efforts to provide personal protective equipment (PPE) for health care workers During this unprecedented crisis, UOAA will continue to monitor the situation and advocate to protect the ostomy community and the brave dedicated workers who care for us. We are in this together!

Ollie the Awesome Ostomy Bear Visits Good Sam and the Ostomy Support Group of DuPage County! If you haven't heard of the Awesome Ollie Bear Project, please visit https://www.awesomeostomy.com/ and read about the great work Dawnette Meredith, and ostomate in Southern California is doing by bringing joy to patients of all ages by donating Ollie Bears to children's hospitals around the country.

Trends in Ostomy Specialty Practice

Via Vancouver HighLife Newsletter

Convexity 47% of nurses in the study reported that 26% to 50% of their patients required convexity. However, many indicated they avoided use of these products during the immediate postoperative period. Nurses who were comfortable with its use in the immediate postoperative period stated they used convexity in patients with poor protrusion such as individuals with temporary loop stomas or in obese patients with retraction or soft, flaccid peristomal contours. Nurses who avoided convexity indicated concern that its use after surgery could cause mucocutaneous separation of the ostomy from the skin of the abdominal wall. Nurses who felt comfortable with it stated they felt less worried about damaging the mucocutaneous junction following introduction of products that employ soft or flexible convexity features. They further opined that the likelihood of developing mucocutaneous junction separation was low whereas the inability to get a consistent seal was high and overrode the small risk of mucocutaneous separation. Both participants and faculty noted absence of research-based evidence concerning the risk of mucocutaneous separation in the immediate postoperative period associated with use of convexity. In addition, both those who did and did not employ convexity during this period agreed protection of the peristomal skin from leakage and exposure to stomal effluent is a priority.

Cleansing the Peristomal Skin and Use of Accessory Products The majority of participants 80% instructed their patients to use only water to routinely cleanse the peristomal skin. They indicated that they counseled patients to avoid routine use of soap because it leaves a residue on the skin that can interfere with the pouch seal. This risk is especially high in soaps containing emollients or other moisturizing products. 41% of nurses advocated use of skin barrier rings to achieve maximum wear time in up to 25% of selected patients. Participants discussed use of skin barrier paste versus barrier rings, and they noted that the paste can be more difficult for some people to use and can cause stinging on denuded peristomal skin. In some instances, participants noted that the use of a skin barrier ring can improve the pouching system seal and protect peristomal skin. When asked what percentages of your ostomy patients routinely use a liquid skin barrier (wipe or spray), 53% used it less than 25% of the time in their practice. Discussion also revealed that some patients used the liquid skin barrier because they believed it improved the pouch seal. Other respondents noted that some patients found that their product supplier sends them this type of product and they use it because they believe it was given to them to help the pouch adhere. Most reported that they did not use liquid skin barriers because some manufacturers of ostomy products have suggested that these barriers interfere with the seal.

Disability and Living with an Ostomy

Lauren Wolfe RN, BSN, CWOCN Macdonalds Prescriptions Fairmont building Vancouver Via Vancouver HighLife

Living with an ostomy shouldn't impact what you are able to do while living your life. Nonetheless, the Canadian government has acknowledged that living with an ostomy means that you spend more time than the average person using the washroom. Meaning that those who have a permanent ostomy or who have been living with one for more than a year qualify for the Disability Tax Credit. This tax credit helps to acknowledge that people with ostomies may experience an added barrier while going about daily activities.

Since using the washroom often does take longer for people with ostomies, many opt to use the handicapped washroom. It provides more privacy, less urgency to rush, and a place to put products. For men specifically, the lack of stalls in men's washrooms presents an additional challenge. Overall, the handicapped washroom is a great option but along with it comes the expectation that one has a visible and obvious disability to validate its use – which isn't always the case with ostomies.

I recently had a young person share their experience with me of using a handicapped washroom, and needless to say, I was quite devastated when I heard what happened. She mentioned how as she came out of the washroom, an older person confronted her regarding her use of the washroom while not physically appearing to be handicapped. So my question to you is what does this mean? And why do people assume that all disabilities must be visible?

Today, many countries have begun media campaigns to promote the idea that not all disabilities are visible. Many signs and promotional material explain that there are a variety of reasons why someone might use a handicapped washroom, choose to sit in a designated seat on public transport, or use a handicapped parking space. These range from ostomies, to chronic pain, to using a wheelchair – and each is a valid reason to use these spaces. Furthermore, no one should have to justify their use of accessible spaces to anyone else.

While at a conference in the UK, I learnt that this issue is universal and that in an effort to combat the issue, the Colostomy Association came out with a sticker saying: "Not all disabilities are visible,". A quick Google search reveals that many other countries and cities have begun to implement signs that inform the public that not all disabilities or accessibility challenges are visible.

I hope that in 2020 we begin to see Canadian cities work towards inclusive and accessible signage to help educate people that not everything is immediately visible.

OSTOMIES ONLINE Some of the Cool Stuff that is on the Internet

By Jonathon Grady Source: Ostomy Halifax Gazette Via Winnipeg Inside Out

I was given the opportunity to speak to the members of Ostomy Halifax about information and resources for ostomates available on the internet. As a fairly recent ostomate with an ileostomy, I had many questions both leading up to my surgery and during my recovery in the last year. I found that the internet held a wealth of resources for ostomates; the trick was finding the ones that were most supportive, positive and inspirational.

My search for information began shortly after my doctor told me that an ostomy would be in my future. As an adult in my mid-forties who has lived with Crohn's disease for almost thirty years, the news, while not entirely unexpected, was still a shock. How would this change my lifestyle? Would I be able to do all the things I did before? Would I be able to swim with my children in the summer? As a high school Drama teacher, would I be able to keep up with the demands of a fairly physical job? Would I still be able to ride my bicycle to work? These were just a few of the questions that rattled through my brain at the time.

Fortunately, the answer to all of those early questions appears to be, "Yes!" As I pass the one year mark since my surgery, I find that most of the things I had been worried about are not much of a worry anymore. I can still do most of the things I did before (and the things I cannot do, I think I will start blaming on age and not the ostomy). I think I am settling into whatever my new "normal" is. It is not the same as before, but considering the alternatives to not having the ostomy, I am happy with my progress.

So what the heck does all of this have to do with the internet/ Simply put, I had to get my head around having an ostomy. I then had to get my head around living with an ostomy. In an attempt to put my mind at ease, I started to look for information that was available at my fingertips: this search brought me to the internet.

Oddly enough, I didn't really start with what you might consider the obvious ones. I didn't begin at sites like Ostomy Canada (www.ostomycanada.ca) and the United Ostomy Associations of America (www.ostomy.org). While both are great sources of information and learning (and well worth checking out), I needed something that was tailored a little more to my needs and desires. This led me to the work of a lot of remarkable bloggers and YouTubers who had many great things to say about living and thriving with an ostomy!

As I started to investigate these web sources, some sites (blogs often) were full of the negative. However, there were some real gems out there—incredibly positive messages that were ground in reality. As someone who likes the outdoors, I started by searching "ostomy" and "camping". My thinking was, "Can I still do an activity I enjoy that is away from the safety of a bathroom?"

Continued

What I found was Ostomy Outdoors, a mix of blogs and videos by Heidi Skiba, an avid outdoors adventurer (ostomyoutdoors.com). To see and read about the things that she was able to do with and ostomy immediately put my mind at ease about becoming an ostomate. From there, I encountered other great sites such as Eric Polsinelli's Vegan Ostomy (veganostomy.ca) and Meghan's Front Butt YouTuber channel (youtube.com/user/TheFront Butttuber), to name a few.

Since my days of these initial searches, these sites and others have become regular stops as I try to understand more about living well with an ostomy. What follows is a few of my go-to links. Have fun checking these out. Just remember that in many cases, these links lead to sites run by regular people who happen to have ostomies. These are not ET nurses or specialist doctors, and their information should never be a replacement for sound medical advice. However, like all of us with ostomies, they are people with insights into living with an ostomy every day.

An extra word of caution. Some of these YouTubers are not shy about their stomas - be prepared when you go to these sights to see it all (stomas, output, you name it!). Many of these people are very open about their ostomies and willing to teach by showing!

Notes from St. Louis By Sheila Reddick

We here in St. Louis are lucky to have UOAA national president Susan Burns as a member of our group, in fact she is our current vice-president. Susan often keeps our group up to date on developments at UOAA as they come across her desk. I recently was able to ask Susan how the organization comes up with the figure of 725,000 to 1,500,000 people in the US who are known to have some kind of either permanent or temporary ostomy at any given time. She answered that to arrive at those numbers, the calculations must be collated from several sources. First, figures are gathered from the 3 main companies who sell ostomy product, Convatec, Hollister and Coloplast. Also, hospitals which are 'ostomy centers' around the country share their numbers of surgeries. Unfortunately the numbers don't include all ostomy surgeries because some operations where stomas are constructed are sometimes listed simply in the 'general surgery' category and not counted as ostomy surgeries done by colorectal surgical specialists. 95% of the manufacturers and hospitals contacted agreed to give UOAA their numbers, but they are not precise.

Thank you, Susan, for answering a question that I've had for a long time.

Here is a great article on the value of Support Groups on our website. The Value of Support Groups as Part of the Rehabilitation of the Ostomy Patient

Getting Ostomy Ready for Summer

Peggy Bassrawi, RN, OAGC Board Member Via Chicago?????

So... summer will eventually get here (hopefully without Covid 19 restrictions) and we can all go outside to walk, swim, barbecue, go boating, travel, etc!! If you have an ostomy of any kind, the summer can have some challenges for us. Everyone perspires more in the summer than the winter and the heat and sweat may cause our appliance to come loose, leak or fall off. There are several things that can be done to protect yourself from an embarrassing accident. First, when you are changing your pouch/wafer, make sure your skin is clean and dry. If necessary, use a hairdryer on the lowest setting for 15-30 seconds to make sure your skin is dry before applying the wafer. Then dry the wafer and your skin again to keep it in place. Try to wear looser fitting and lighter weight clothes in the summer so as not to put pressure on your stoma. The pressure can cause more sweating and lead to your appliance coming loose. If you have had issues with leakage during cooler weather, you can always use pink tape to keep everything in place! It is also a good idea to window pane your wafer if you are planning to go swimming... you can do this! Wear a suit with a pattern or for men looser fitting shorts! (no speedos!). Before you go into the water, empty your pouch. After you are finished swimming it is sometimes a good idea to change your pouch, so make sure you have an extra one with you. Finally, it is most important during the warmer months to hydrate more than normal. Water is the best beverage!! While coffee, tea, soft drinks and lemonade are fine for occasionally, these beverages may have too much sugar which is not healthy! If you feel thirsty, you are already heading toward dehydration. Keep a glass or bottle of water with you all the time. If you feel light headed-go inside immediately and push fluids. Take care of yourself and enjoy the warm weather!

DEHYDRATION CAN DRAIN YOUR MIND AND MOOD SOURCE:

AARP Magazine Via Tucson Courier

Feeling out of sorts, but not sure why? You might be dehydrated. Two new studies found even mild dehydration comes with big consequences: altered mood, impaired memory, trouble concentrating, fatigue, headaches, and anxiety. While the reasons for these symptoms are unclear, researchers at the University of Connecticut, Human Performance Laboratory, noted that dehydration causes changes in electrolyte balances in the blood as well as serotonin levels and mood. How to tell if you're dehydrated? Check the color of your urine. "Anything darker than a pale, straw hue means you need to drink more," says study author Lawrence Armstrong, PhD.

UNITED OSTOMY ASSOCIATION OF GREATER ST. LOUIS

Our mission at UOASL is:

- To offer the opportunity to persons who have had colostomies, ileostomies, urostomies, or alternate procedures to meet with others who share similar challenges of adjustment and for sharing of ideas and knowledge.
- To aid the ostomate in recovery and rehabilitation.
- To provide educational opportunities to medical, nursing, and lay groups through lectures, demonstrations, and exhibits regarding care of the Ostomy patient.
- To provide the ostomate with volunteer services and social activities.
- To provide hospital visits to the patient, before and / or after surgery, at the request of the patient's physician.
- To maintain close contact with appliance manufacturers, also local pharmacies.
- To provide information about the availability of products to ostomates and the medical profession.

ARTICLES AND INFORMATION PRINTED IN THIS NEWSLETTER ARE NOT NECESSARILY ENDORSED BY THE UOASL AND MAY NOT BE APPLICABLE FOR EVERYBODY. PLEASE CONSULT YOUR DOCTOR OR WOCN (ET) FOR THE ADVICE THAT IS BEST FOR YOU.

AFFILIATION

UNITED OSTOMY ASSOCIATIONS
OF AMERICA
1-800-826-0826 www.ostomy.org

AMERICAN CANCER SOCIETY
4207 Lindell Blvd.
St. Louis, MO 63108
1-800-ACS-2345 www.cancer.org

Membership Benefits:

Education **Mutual Support from Fellow Ostomates**
Visitation Program **Conferences Country-Wide**
Product Information **Local Meetings and Programs**
Ostomy Guide Books and Informative Literature
"Live and Learn" Our Own Publication

CHAPTER MEMBERSHIP APPLICATION FORM

NAME:_____

SPOUSE'S NAME:_____

ADDRESS:_____

CITY:_____

STATE:_____ **ZIP CODE:**_____-_____

PHONE: HOME: (_____) _____ **OFFICE (_____)** _____

OCCUPATION_____ **e-mail** _____

YEAR OF SURGERY:_____ **DATE OF BIRTH:**____/____/____

Please check all applicable information

Type of ostomy: **( ) Colostomy ( ) Ileostomy ( ) Urostomy**

( ) Continent Ileo ( ) Continent Uros

( ) Other (Specify):_____

Meetings: ( ) Send meeting notices ( ) Don't send meeting notices

Help: ( ) Other Activities _____

Assistance **( ) Request *Complimentary Membership***

Medical Profession ( ) Doctor ( ) RN,WOCN ( ) Other _____

UOASL Chapter Membership Dues: (Effective Jul 2006)
$12.00 annual

Make check payable to U.O.A.S.L.
SEND CHECK TO: Rick Haley
907 Pevely Pointe Dr. Apt. 106
Pevely MO 63070

(ANY CONTRIBUTIONS OVER $12.00 ARE TAX-DEDUCTIBLE AS WE ARE A NON-PROFIT ORGANIZATION)

UOAA United Ostomy Association of Greater St. Louis

949 Chestnut Oak Drive
St. Charles, MO 63303

UOAA United Ostomy Association of Greater St. Louis

Local website is www.uoaastl.org

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Don't look back,
you're not going that way.
Mary Engelbreit

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LIVE AND LEARN – Summer 2020

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