

Ostomy Outlook



LETTER OF THE OSTOMY ASSOCIATION OF THE MINNEAPOLIS AREA	
Volume I, Issue X	
June/July 2018	
Date:	Monday, June 18 2018
Time:	6:00 PM-8:00 PM
Place:	United Methodist Church of Peace 6345 Xerxes Avenue South Richfield, MN 55423 612-866-0069
Program:	Antless Picnic! Note: Change of time. Arrive early. Dinner is on us: Fried chicken, potato salad, etc. Please bring 1-3 corny jokes.
Date:	Monday, July 16, 2018
Time:	6:30 PM – 8:00 PM
Place:	Our speaker for July will be Julie Abbott. She was diagnosed as a young child with Spastic Diplegia, a form of Cerebral Palsy. After 33 years of countless doctor's visits, medical procedures, unnecessary medications and surgeries, she was correctly diagnosed with Dopa Responsive Dystonia (DRD) and given a new life!
Program:	Jean is the author of <i>Misdiagnosed: My Thirty-Year Struggle with a Debilitating Disorder I Never Had</i> and has appeared on the <i>Today</i> show, <i>Good Housekeeping</i> and the U.K.'s <i>Daily Mail</i> .



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|--------------------------|--------------------------|---------------------|--|
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The Ostomy Outlook is printed and circulated for people with Colostomies, Ileostomies, Urostomies, and alternative procedures, heir families and other interested Persons.

Our new website address is: ostomyminneapolis.org

Ostomy Association of the Minneapolis Area Membership Creed

As members of this group, it is important to be ever mindful of our many blessings: our understanding families and friends, our homes, and our way of life. Most of all, as ostomates we need to be ever mindful of the life which has been given back to us and to find the courage to face our daily challenges. Let us continue to be concerned for people who need our help, our support, and the knowledge that we have gained. Let it be our task to reach out to others and to ourselves. May we do this in a spirit of fellowship and fond regard.



The President's Corner

PRESIDENT'S LETTER: (speakers in April and May)

Anne Lowry gave a fascinating talk at our April Meeting. Besides answering many questions from our group, she explained what "robotic surgery" was and her trials learning how to do the complicated procedure. It's always a treat for us to hear from such a renown surgeon.

Recap from Bob Bartlett, Psychologist, speaker for our May meeting.

Bob Bartlett talked about how we cope with difficult health issues and emotional ones that often accompany them. He has been to speak to our group several times over the years and he always has more information to add that is valuable. A very good story teller, he made relatable points for us to take away in a hopeful message.

After he spoke, we got into three different groups with people with colostomies, ileostomies and caregivers in another. Everyone had a chance to share their stories and questions. and our question to focus on was how/when did things begin to turn around for you when facing life with an ostomy? It brought up very fruitful discussion in each group.

**Bob Bartlett is a licensed family and marriage therapist practicing at Phoenix Process consultants in Eden Prairie. If you would like to talk to him directly, you can reach him at 952-922-8822.

New Business:

Thank you for all of you who have responded to our annual membership drive. It is so appreciated to be able to look ahead and know that we can provide for future meetings and manage our bills.

Also, these people have donated extra funds for youth rally or OAMA

Thank you for your generosity!

Carole Ann Barron

Dave Dovenberg

Don Heinrich

Ann Henzlik toward the youth rally

Sue Norby: in honor of her 15 years with an ostomy anniversary. Congrats!

Ed Scinto: In memory of Ruth Seifert

Maeve Murphy donated in honor of her 24th anniversary with an ostomy. WOW!

We have about 32 members who have still not paid their membership dues. We thank you for your past support and please let us know if you do not want to receive the newsletter any longer. We are financially sound thanks to your generosity

Our board is looking out for our best interest in the future. In 2019 we have the national convention in Philadelphia and we are usually able to help our members pay for their registration if they can attend. so start saving your dimes now for the next conference held in August 2019. More details on that later.

TREASURER'S REPORT from Brenda Elsagher

Treasurer's Report and Membership, Brenda Elsagher


Thanks to the many members that join on line and at meetings. We appreciate seeing you and hearing from you!

Currently we have 103 Members and we have 118 WOCN nurses on our email list. If you know of a nurse that needs our newsletter, please let me know.

Thank you for the help from our sponsors and members:

- Coloplast
- Hollister
- Colon and Rectal Surgeons
- Handimedical
- Colon Cancer Coalition (GYRIG)
- Minnesota Gastroenterology




No one is ever turned away for not having the financial means to support our \$25 membership yearly. Just come to our meetings and be a part of us. You are always welcome! Our website is getting more attention all the time. If you have suggestions about our newsletter and website, please feel free to send them to Carol Larson or myself. !

Get Ostomy Answers! 

The Phoenix magazine provides answers to the many challenges of living with an ostomy. From skin care to nutrition to intimacy, in-depth articles are written by medical professionals, ostomy experts and experienced ostomates. Subscriptions directly fund the services of the United Ostomy Associations of America.


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Treats and water until November

- July 16 treats: Rich Trainer
water :Nancy Simpson
- Aug 20 treats: Carole Barron
water: Rich trainer
- Sept 17 treats: Char P
Water: Joel Branes
- Oct 15 treats: Carol Larson
water Mark Levin

**If you would like to suggest a future program, please contact: Carol Barron barronski@aol.com

***If you have weather questions, please call 952-882-0154

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The logo for the Colon Cancer Coalition, featuring a stylized blue star with a white outline and the text 'COLON CANCER COALITION' to its right.

GETTING TO KNOW JOEL BRANES



Every person dealing with an ostomy situation has a different story. My story starts with me being very healthy as a child, student, young and middle age. I know my friends and family would sometimes have called me a "health nut". So, to be sick enough to agree to have my colon removed was quite a shock to everyone, me most of all.

As a student I was an athlete. In college, I played football and wrestled. Throughout my life I was a runner, doing several marathons. I also served as a Captain in the Army. After leaving the Army, I studied and became a chiropractor. This profession helped has a significant focus on natural health alternative and choosing a healthy lifestyle.

Around the time I was in my 40s, I began to experience rectal bleeding and was diagnosed with ulcerative colitis. Eventually hospitalized for dehydration, they began a course of steroids, which did not solve the problem. When they began talking about surgery, I opted to contact a Chinese acupuncturist, who came to the hospital to treat me, with great success. I was quickly healed and did not have one symptom or restriction for almost 25 years.

In November of 2016, I was pheasant hunting in South Dakota when I started passing small amounts of blood. My first thought was never colitis returning. Things progressed very rapidly and in a few days I was once again hospitalized. This time, I immediately contacted an acupuncturist to augment the treatment, getting permission from the hospital to do this. This time, they were very receptive to me being treated with acupuncture right in the hospital. However, neither the drug treatments nor the acupuncture helped the condition. After

being in the hospital for 3 weeks, my condition had deteriorated significantly, and I had my colon removed. This began my transition into a new normal of equipment choices, bag changing, and living life with an ostomy.

In January of 2017, my wife and I went to Mexico for two months. During the first surgery, Dr. Belzer, my surgeon, had left a 6-8 inch remnant of rectum, leaving me with the option of reconnecting come day. For some reason, I began experiencing bleeding from this area, after being in Mexico for two weeks. It came on very quickly and I was losing a lot of blood. We very quickly decided I needed to see someone and opted not to go to a Mexican hospital, but rather flew home, feeling very relieved when I arrived without any incidents on the plane. After several transfusions, and a few weeks waiting period while my bleeding subsided, I underwent a second surgery to remove the remainder of the anal remnant.

I continue to have to daily monitor my hydration level as the doctor is speculating that letting myself get dehydrated had an impact on this second episode. Basically, I am able to lead a full and active life. I am in the American Legion Color Guard and march several miles in parades, I can sit in a tree stand for hours, have gone fishing in Alaska, ride my bike for several hours at a time, and grow and tend grapes in my vineyard and spend hours working in the field. I have survived some huge ordeals but thank my Lord and Savior for the privilege of being alive, seeing my grandchildren grow up, and living this new normal life of mine. Written by Joel Branes



From Minneapolis to Puerto Rico

In September of 2017, Puerto Rico was hit very hard by Hurricane Maria, causing destruction throughout the country. Today, only half of the country has electricity restored. A February issue of the Ostomy Association newsletter featured an article about the shortage of ostomy supplies in this country.

Martha, a retired Puerto Rican and president of the Ostomy Association of Puerto Rico, has been collecting and storing supplies at her apartment.

I reached out to her to ask if additional supplies would be helpful.

She responded, "It is not easy trying to cope with the situation. I really appreciate your interest in helping us." Our Ostomates are in need of supplies as we are running out of health care."

I contacted several members from our Minneapolis club and Handy Medical.

We collected two large suitcases of ostomy supplies, including fifty pediatric sets. Martha had stated that the postal service is back working but with difficulties. A friend of ours owns a home in Puerto Rico. They were making a trip there in March, and offered to deliver these suitcases with the supplies. Martha was very thankful for these donations. She also stated that she could use any supplies that our club could donate.

Please save your extra supplies and in the future, when this couple is planning another trip, we will ask you to bring your supplies to a meeting.

Thank you to those who donated to this first shipment. Also, thanks to Handy Medical for their contributions.

The Ostomy Association of Puerto Rico also says a big "thank you." Joel Branes

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Patient Power –

If you have any ideas or issues you'd like us to address, please send them in to the newsletter editor or directly to us, Darlene Hafner and Anne Marie Kronick." You can reach us by emailing dmhafner@yahoo.com or amkronick@comcast.net



IT'S TIME FOR A CHANGE

Back in November my husband casually said, "I think it would be a good idea to update "just a few rooms." We sat down and agreed that we'd been in the house for 21 years and that it was time for a change and some things needed to be upgraded. We needed new windows, wanted to change the wood burning fireplace to gas, needed to replace the 20 year old carpet and the walls needed a new coat of paint. Of course, like any remodeling job, it got bigger than the original plan, took longer than expected and had our disagreements about details, paint color and carpet texture. All of a sudden those "few rooms" turned into the entire first floor getting new carpet and all new paint. And while we're at it, let's change out those 30 year old wood railings to a more modern wrought iron one.

I kept thinking to myself, how did this "simple" project become a lot bigger than I anticipated? So many decisions had to be made from wall color to knobs to the type of wood for the railings. Let's face it, who can really make a major carpet decision when the sample is 6 X 6 inches? So weeks and months went by before the project was complete.

In the end, the project turned out great and we both decided that we liked all the updates and how it turned out.

When I was going through the remodeling process, for some reason I kept thinking there was an analogy of how many of us went from a "simple update" to a very long complicated journey to our ostomies. Maybe for some of us it started off as a simple routine colonoscopy that ended in colon cancer and eventually a colostomy or a simple procedure such as mine, having an abscess lanced, and ending up in the hospital for 6 weeks, with life threatening peritonitis and finally an emergency unplanned colostomy. None of us woke up one day saying, "I think I'll get an ostomy today". Some of us planned for the "remodeling" process while for others the "remodeling" process took on a life of its own becoming bigger and longer than expected. All of us had more decisions than we ever bargained for. The decisions about the various pouches, wafers, creams, powder, seals and wipes seemed endless. Maybe even some of us felt we were going through a complete "tear down," starting our lives all over again with a body that was brand new to us.

Completing a house project, just like having a new ostomy, not only takes a lot of patience but at one point we have to be comfortable with the final result and be confident that we made the right decisions based on the information we were given.

Do I really like the new gray walls rather than the dark red I was used to? Do I miss that glass coffee table that I just sold on Craigslist? I can second guess myself but in the long run I enjoy the update. It might take a while to get used to, but I now have more light in the rooms and its brighter and more cheerful.

Yes it can take a while to adjust to a "re-model" or get used to our new bodies after an ostomy, but we have to believe that it was the best decision for us. We hopefully can enjoy a new lease on life, be more active with less pain and more energy than in the past. I hope for all of us our

lives are a little more brighter and more cheerful now, just like my new rooms.

UPDATE: After 17 months (Yes, 17 months!) of calls, letters and appeals I FINALLY received my money back from my insurance company for an out of pocket expense. Diligence and persistence paid off but not without a lot of frustration and an awful amount of time! Hang in there if anyone is going through the same. Written by Dar Hafner



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JULIE'S CORNER-

Prepare for Take Off

Pack These Tips and Advice When Traveling with an Ostomy

by Wil Walker, Manager, Clinical Education, Hollister Incorporated

Traveling with an ostomy does not have to slow you down. Whether you're traveling by car or plane, here are some suggestions on how to make your trip worry free.

How many extra ostomy supplies should I pack when traveling?

When traveling, you should pack double the number of supplies you would normally need to make sure you have plenty of pouches and supplies on hand. That way, you are ready for the unexpected, such as a delay in returning home, lost pouches, or changes in climate and environment that call for more pouch changes than usual. In the event that you do need

additional supplies while traveling, most manufacturers have products available around the world. Before you leave home, check to see where you can purchase new supplies in the areas where you plan to travel.

Which supplies should I keep with me in my carry-on when I fly?

Your short-term items should go in carry-on luggage so they remain with you at all times and are within easy reach. It's advisable to keep these supplies in a separate, small travel kit to make visits to the toilet simple and discreet.

On long car trips, what should I do about emptying my ostomy pouch?

It could be very messy to attempt emptying an ostomy pouch during a car trip, especially on bumpy roads without the correct type of receptacle in which to empty it. Frequent restroom stops are recommended for the most hygienic emptying.

What should I expect when going through airport security?

Pack all of your ostomy supplies in a separate, small travel kit that can go through security independently from your other carry-on items. Your hand luggage will be inspected at the security baggage check before boarding an aircraft. If you have any prescription drugs with you, have your healthcare professional prepare a card explaining that they are medical supplies. You may be searched before boarding the aircraft, so be prepared to explain about your stoma and ask to be searched in a private area for medical reasons.

I heard that I can get a special travel certificate explaining what I am bringing on the plane. What is this and how do I get one?

Travel certificates available through ostomy associations are available to help explain your need to carry ostomy pouches, skin barriers and medications. It is recommended to search online for travel certificates available for ostomy patients. Read: UOAA's Travel Communications Card

What if I have to use the restroom when the "fasten seat belt" sign is on?

Government and airline restrictions could interfere with your access to the restroom during flight. Plan accordingly by emptying your pouch before takeoff. You may also want to consider a private conversation with the flight attendants to inform them that you require restroom trips throughout the flight, and ask them to help you plan accordingly based on your flight schedule.

Will the pressure in the cabin affect my pouch?

A change in cabin pressure on a plane could create a small amount of gas in the pouch. You may consider using a pouch that includes a filter while traveling to help deodorize and slowly release gas from the pouch.

Helpful Links: Hollister Travel with an Ostomy: securestartservices.com/travel

Hollister Secure Start services provide ongoing support to people living with an ostomy.

We are here to help! Call us today at 1.888.808.7456. Editor's note: This educational article is from one of our digital sponsors, Hollister Incorporated. Sponsor support along with donations from readers like you help to maintain our website and the free trusted resources of UOAA, a 501(c)(3) nonprofit organization

Exercise your fitness options with these helpful tips

by Wil Walker, MBA, BSN, RN, WOC Nurse Manager, Clinical Education, Hollister Incorporated

When is it safe to start exercising after ostomy surgery?

Stoma surgery is a major event that should not be underestimated. The first few weeks or even months following the operation may be difficult as you adjust gradually to having a stoma. The easiest and most effective form of exercise can be walking. It's best to check with your healthcare provider to determine the right time for you to begin exercising, as every person can be different.



I'm nervous about doing sit-ups and crunches because I have heard that I could develop a hernia. Are there precautions I can take to avoid this?

There may be a risk you will develop a hernia around your stoma that can be associated with straining or heavy lifting during strenuous abdominal activity. You can help prevent the development of a peristomal hernia by taking certain precautions. Keep your weight in check and talk with your surgeon before resuming any abdominal exercises.

How will I know that I am sufficiently hydrated?

One good sign of being well hydrated is passing clear or straw-colored urine throughout the day. Dehydration can be a concern for overachievers, whether they have stomas or not. Drink plenty of fluids at every opportunity to avoid problems with your stoma and with dehydration.

I am still very tired after my surgery. What kind of exercise can I do to start out?

Begin by walking in your house. Special videos and DVDs, or even just some invigorating music will help set the pace. You might practice going up and down stairs to increase stamina and endurance. But, if weather permits, walk outside in the fresh air to help boost your physical and mental spirits!

I love swimming but I'm nervous that my pouch will become loose in the water. Is there anything I can do to make sure this doesn't happen? It is recommended to "test" your pouch. Sit in bath water for a while and assure yourself that the seal stays snug and leak-free.

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OAMA
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