

Ostomy Outlook



LETTER OF THE OSTOMY ASSOCIATION OF THE MINNEAPOLIS AREA	
Volume II, Issue I	
July/August 2018	
Date:	Monday, July 16, 2018
Time:	6:30 PM – 8:00 PM
Place:	United Methodist Church of Peace 6345 Xerxes Avenue South Richfield, MN 55423 612-866-0069
Program:	Our speaker for July will be Jean 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! 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 <i>U.K.'s Daily Mail</i> .
Date:	Monday, August 20, 2018
Time:	6:30 PM-8:00 PM
Program:	"Rap" session sharing our stories about our experiences learning to live and travel with our ostomies.



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The Ostomy Outlook is printed and circulated for people with Colostomies, Ileostomies, Urostomies, and alternative procedures, their 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)

New Business:

Notice: This is a "special issue" of our newsletter. Last month only the people who had email got a copy, so we are combining July's and August's combination and sending this out to everybody.

Our antless picnic was a success and fun for all!

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:

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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 .

!

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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 and the text 'COLON CANCER COALITION'.

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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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 it's 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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Finding Confidence and Rocking Your Own Style with an Ostom By Tricia Hottenstein

I was packing to head out on a short vacation to Atlantic City and had all my outfits ready in my brand new suitcase. But when I went to pack my swimsuit, I started thinking about walking around at a hotel pool with my ostomy bag sticking out. Something about a hotel [pool](#) as opposed to just walking on the beach made me uneasy. I figure I don't know the people on the beach and they'll never see me again. But in a hotel for several days? Those people would recognize me. They'd see me dressed up for a nice dinner and know that underneath all that jewelry and makeup, there was a person with an ostomy bag glued to their stomach. A person who earlier in the day had a wet ostomy bag sticking out between

their swimsuit pieces. And let's be honest. A wet ostomy bag is a revealing ostomy bag. There's no questioning what's hiding inside of it. Something about that wasn't okay with me.

Generally speaking, I feel pretty confident about my ostomy. It saved my life and I went from a love-hate relationship with it, to a genuine love of it, to more of a state of ignorance that it even exists. I'm not shy about telling people my situation and I will often show it to people who ask questions. But when it comes to swimsuits, the struggle has been a little more mental.. And then, hallelujah! The high-waisted trend hit stores, and I found a happy medium. A high-waisted bottom to cover most of my bag while still allowing it to breathe, and a cute colorful top that would hopefully draw attention away from the bag peeking out from my bottoms.

I love that I didn't need to strip a whole wet swimsuit off in order to empty my bag, and I could easily flip it out after the pool to dry it off (which is a necessity in order to keep my sensitive skin from getting angry). The high waist also gave multiple coverage options and I could choose when and how my bag would be displayed. I could tuck it into the bottoms and feel secure, or leave it out over top of the suit if need be. I chose to secure my bag slightly flipped up inside the bottoms with just the top sticking out. Now this I could rock. And I did. But around complete strangers who would be seeing me over and over again, while never actually talking to me to understand who I was and what I've been through? It bothered me.

I bought a pretty cover-up. I tried on several new suits, but none worked the wonders I'd hoped they would. I even considered stopping on the way to the shore to keep trying. And then the lights of Atlantic City sparkled before me, and the tropical drinks and palm trees were calling me from the pool. So I went for it. I wore the cover-up and walked to the pool. Of course, I got stuck with several people in the elevator and noticed their eyes glancing down, and my fidgeting was more than noticeable.

I walked in the pool room and found a chair in the corner. I ordered a drink, hopped in the hot tub, and looked around. And I noticed every single other female in there looking as insecure as me. Ladies with towels draped around them the second they were out of the water. Women with tee shirts instead of swimsuits. Some just sitting on the outskirts, partially hidden by palm trees, in regular clothing. And suddenly I was okay. Forget this bag on my stomach. Every single person has something about them they don't always love. I've got stretch marks I don't worry about, and plenty of extra flab that doesn't bother me. But for some reason I was getting caught up over this little protrusion on my stomach; a scar of a war I fought hard against and finally won. And I love this thing!

I was honestly upset with myself over the few days for the waver in my self-confidence. I got out of the hot tub, walked around to the pool, and held my head up a whole lot higher. And everyone who's eyes glanced downward? They looked at me genuinely, some smiled. Because people who rock their scars in public have already changed perceptions. Chronic illness is becoming less and less of a taboo subject. We're shaking the world by the shoulders. And THAT is beautiful.

Tricia Hottenstein blogs about life as a mother and living with an ostomy at stomama.com

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