



Ostomy Outlook



NEWSLETTER OF THE OSTOMY ASSOCIATION OF THE MINNEAPOLIS AREA

Volume XLXVI, Issue II

February/ March 2017

Date:	Monday, February 20, 2017	
Time:	6:30 PM-8:00 PM	
Place:	United Methodist Church of Peace 6345 Xerxes Avenue South Richfield, MN 55423 612-866-0069	
Program:	Mardi Gras Party!!!! with Rap Session-Julie Powell	
Date:	Monday, March 20, 2017	
Time:	6:30 PM – 8:00 PM	
Place:	United Methodist Church of Peace 6345 Xerxes Avenue South Richfield, MN 55423 612-866-0069	
Program:	Come meet Darcy Helder and Krista Harvego from Coloplast. They will discuss the new Mio Convex products with three different levels of convexity and also present the new or soon to launch, Brava Protective Seals. Krista will review the CARE program and how she works with new patients. They are happy to support you and look forward to meeting everyone.	

President:	Rich Trainer	952-888-7315	goldenstrainer@yahoo.com
Vice-President:	Frank Moriarty	763-557-5712	moriartyf@earthink.net
Secretary:	Marilyn Carlson	952-941-9148	mcarlson@easween.com
Treasurer and Membership:	Brenda Elsagher	952-882-9882	brenda@livingandlaughing.com
Newsletter Editor:	Nancy Hagfors	952-237-6465	pitplayer@q.com
Hospitality:	Anne-Marie Kronick	612-920-6662	
Patient Advocate:	Dar Hafner	952-835-4599	dmhafner@yahoo.com
ASG Representative & Newsletter:	Carol Larson	952-934-3804	caroldavidlarson@aol.com
Social Media contact:	Nancy Hagfors	952-237-6465	pitplayer@q.com

Mailing Address: Ostomy Association of the Minneapolis Area P O Box 385453, Bloomington, MN 55438-5453

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

Hi Everyone!

I hope everyone is having a good year.

Our weather last month on Jan. 16, 2016, was hard to assess. At 5:00 p.m. it didn't seem so bad, but when we came out of our meeting, it was like ice skating going to our cars!

** Be sure to call 952-882-0154 for weather information and whether our meetings have to be cancelled.

We had a small group (about ten people) attending our meeting, but we had a rap session last month that was good. I think we all learned something. A new member came to the meeting with a lot of questions we all took turns to answer.

Dues are due in March, 2017. That is the new year for our club. You can pay your dues by clipping it out of the newsletter.

We have a lot of good people that are going to talk. If you can bring treats, please let Marilyn Carlson know. Her number is 952-941-9148.

Best to All, Rich



Thank You!

Marcene Asleson, 40 year celebration with an ostomy.
Thanks for your additional donation.
In Memory of Ruth Carlson, mother to Marilyn and Mike
Carlson, donations were made to OAMA

HAPPY★NEW★YEAR

Patient Power by Darlene Hafner



YOU HAVE THE POWER TO APPEAL

So I turned 65 in January and many well-wishers commented saying, "Welcome to Medicare" and "Way to go, you're on Medicare." Many friends said, "You'll like Medicare....they'll pay for this; they'll pay for that" and others even said, "I don't pay a dime."

Before I turned 65, I was diligent in going to numerous Medicare meetings. I made an appointment with an insurance broker to go through the various plans and costs, making sure I chose the one that fit my needs as an ostomate and a person who has Crohn's Disease.

So imagine my surprise when I ordered a refill of my tincture of opium and got a call from the pharmacy. My previous \$10 co-pay was now full price of \$130 totally out of pocket and NOT covered by Medicare OR my insurance. What!?? I thought, that couldn't be true. There had to be a mixup. I did all my homework to make sure my prescriptions were covered.

Come to find out, Medicare doesn't cover the drug. Therefore my insurance wouldn't cover it either. Apparently Medicare feels an opium product should not be covered but they apparently don't understand the necessity of it for some people like the two of us who have very little intestines left and have nutritional issues.

To clarify, both Anne Marie and I use the drug. If I don't take it before I go to bed, I have to empty my pouch about 5 times a night, disrupting my sleep and feeling groggy the next day. It helps me nutritionally as well, as the food passes way too fast if a person only has a few feet of intestines and the food and vitamins cannot be absorbed adequately. This drug keep us healthy and avoids the possibility of being on TPN via IVs to get our nutrition. As I grudgingly slid my credit card through the machine I thought to myself, "In one month's payment of \$130, I'm paying over what would have been a year's worth." This just didn't seem right! So my "Be Proactive" attitude kicked in. I began making the calls. To Medicare, to my insurance company, to the pharmacy, the nurses and my GI doctor. The missionhopefully NOT Mission Impossible...was to appeal.

Thank goodness for my "partner in crime" and co-writer Anne Marie.

She said she had the same issue and after many denials and LOTS of perseverance her tincture of opium was approved. With hope and tenacity I will continue the appeal until "they" understand why I need it.

When you hear that a test, procedure or a drug has been "denied" put on your Be Proactive hat and try to appeal it. Maybe it won't work in all situations but at least a person can feel proud that you tried and did the best you could to make the "powers that be" understand the needs of people who have ostomies and intestinal diseases. Together we CAN make a difference.

Dar

Attention-Very important!

****Have you had surgery in the last five years? UOAA has been working with American College of Surgeons (ACS) for the last six years to develop education programs that surgical professionals can use with their patients. Only the group response will be reported (not individual responses.)

These resources are designed to help new patients safely care for themselves after their operation. ACS needs patient input to better understand the experience surrounding surgery. Survey data is being collected in order to help people who have ostomy surgery in the future. Please contact Marilyn Carlson. Surveys are due in March.

Getting to Know Me! Carole Barron



Hi Everyone,

My colostomy celebrated it's 1st anniversary on October 19th. I was diagnosed with rectal cancer on June 17th and had chemo and radiation during the summer. Starting in high school I had problems with Crohn's and had my 1st small bowel resection while in college. After finishing school I worked as an RN in Peds for several years before transferring to OB. I spent 44 years working at Methodist Hospital in Saint Louis Park. It was a wonderful job with many caring nurses who still remain some of my closest friends and best support. I met Rich and Joanne Trainer through work.

I met my husband Ron who lived in the same apartment building as my sister and I. He was an English teacher at Richfield High School. We have 3 children who all live close by in Bloomington. In 2014 he was diagnosed with esophageal cancer and only lived 3 ½ months. I have remained in our house and kept very busy with 5 grandchildren, family and friends. My daughter has a new puppy and I do doggy daycare. Annie is very energetic.

So far my colostomy has not been a problem because I do not have the urgency I had. When I entered a new building the first thing I did was locate the bathroom in case. Since 2007 I have had cardiomyopathy and heart failure. The chemo made it worse, so after 3 opinions I did not have chemo after stage 3C cancer. Just hope and prayers.

Last June, 9 of my family members and I drove to Yellowstone in 2 cars and the trip went very well. I love to travel. In January, my 5 grandchildren, 3 kids, and I are going to Disney World. It will be my first flight with a colostomy. Life has been busy, but I am optimistic that things will continue to go well. It may be the determined, North Dakota German in me.

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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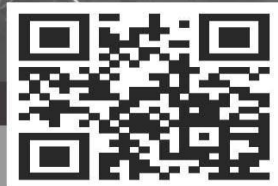
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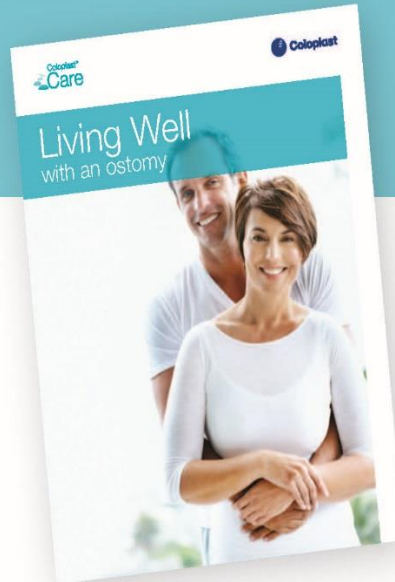
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JULIE'S CORNER- **When to Contact an Ostomy Nurse**

Living with an ostomy can be a bit challenging at times. One of the most important things to remember is that everyone's ostomy is different. The following are reasons to contact an Ostomy Nurse for advice.

- A change in size or appearance of the stoma.
- Skin problems around the stoma including a rash, open sores, redness or weeping.
- Ongoing leakage of the pouching system.
- Weight gain or loss that may cause difficulty with the pouching system.
- A cut in the stoma.
- Difficulty in getting an appliance to secure to the skin around the stoma.
- General questions regarding ostomy care and management. Issues may revolve around diet, bathing, activity, odor, diet and travel.
- Contemplating a change in pouching system.

From Julie Powell WOCN *Remember to bring all extra supplies to our meeting.



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- Providing the best care for the individual
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<http://www.colonrectal.org>

JULIE'S CORNER: FROM THE UOAA

Ostomy Travel Tips

New: See an [Extensive List of Travel Tips from TSA](#) – the US Transportation Security Administration.
See the [November 2015 Letter from TSA](#) with Travel Advice for the 2015 Holiday Season.
Also download UOAA's [Travel Communication Card](#) as an aid in dealing with airline security.

In these days where extra precautions for security are being taken worldwide, it would be wise for traveling ostomates to do advance planning in order to avoid possible problems. Some suggestions are:

1. Pre-cut all pouches at home, as you may wish to avoid having scissors in your carry-on luggage (see [additional comments below](#)).
2. Pack ostomy supplies in at least 2 places – carry-on and checked luggage.
3. Take extra supplies in case you are stranded where supplies may not be available.
4. A statement from your physician stating your need for ostomy supplies might be helpful. Also a statement advocating a private area be used in case of an extended search.
5. If traveling to a foreign country it is a good idea to have critical ostomy information written in their language. One of the 70 member associations of the [International Ostomy Association](#) (IOA) may be of help with this translation as well as with locating supplies while visiting their country.
6. A copy of the book "[Yes We Can](#)" (no longer in print but copies may be available) has many helpful hints and advice for traveling and also has a dictionary of ostomy terms translated to several different languages. There is important contact information for resources worldwide as well as a wallet-sized statement written in 11 languages that asks for privacy if a search is to be conducted.
7. One ostomate reported a very positive result from carrying photocopies of the catalog pages displaying and explaining his equipment. When a searcher asked about the items found on a hand search, he was able to explain their function without a long conversation that would hold up others in line. Our experience has been that over time the TSA agents are much more knowledgeable and sensitive to these personal care products.

About carrying scissors on board aircraft: For domestic flights within the United States, you are free to carry scissors in your carry-on, as long as the cutting edge is no longer than 4 inches. Initially, after Sept 11, 2001, pointed metal scissors were banned from carry-on luggage worldwide. In the U.S., the Transportation Security Administration (TSA) [declared in December 2005](#) that scissors with cutting edges up to 4 inches are allowed. Previously, in August 2005, the TSA had also declared a [special allowance for "ostomy scissors"](#) but that ruling was effectively superseded by the Dec 2005 ruling,

which states simply that anybody can carry scissors with blades up to 4 inches. Meanwhile, if you travel outside the U.S., you may face more severe restrictions on carrying scissors. For [flights departing Canadian airports](#), you can carry scissors in your carry-on, but the blades must not exceed 6 cm (2.4 inches). Other countries may still prohibit scissors in carry-ons entirely. So, if you're traveling internationally, unless you're sure of the rules in the countries you'll be flying through, it's best to avoid scissors in your carry-on (you can always pack scissors in your checked luggage).

Restrictions on liquids, gels, aerosols: The well-known [3-1-1 Rule](#) requires that items classified as liquid, gel or aerosol must be carried in containers no larger than 100 mL (3.4 ounces), and you can carry only as many of these as fit comfortably into a single one-quart (one-liter) zip-top clear plastic bag. These rules are generally enforced worldwide. The most important ostomy supplies, such as pouches and wafers, are not liquids, gels or aerosols, so they aren't subject to the 3-1-1 rule, and you can carry as many as you want in your carry-on. Some related ostomy products (liquid deodorants, remover wipes, tubes of paste, etc.) do fall into the liquid-gel-aerosol category. If you need to carry a few of these on the airplane, it's usually easy to fit them into your zip-top plastic bag to comply with the 3-1-1 rule. If you need more of them, you can pack as many as you want in your checked luggage. Larger quantities of liquids-gels-aerosols that would exceed the 3-1-1 limit but are medically necessary and must be carried on board the plane are [allowable](#), but must be declared at the security checkpoint and require additional screening.

Full Body Scanners ([Advanced Imaging Technology](#)): While early use of these scanners sometimes caused embarrassing incidents for ostomates, as in a [well publicized November 2010 case](#), UOAA and other organizations have helped to educate the TSA on the needs of people with ostomies and other medical conditions. As a result, ostomates have no reason to fear the scanners any more. It's a good idea to empty your pouch before entering the security line, so there will be little to feel if a pat-down is done. The millimeter wave scanners are sensitive enough that even an empty ostomy pouch will usually be detected. Therefore, you should be prepared to state that you have an ostomy when you get scanned. If you'd rather not say this out loud, you can carry one of our blue [Travel Communication Cards](#) while passing through the scanner. TSA officers are trained to know what an ostomy is. The procedure is very quick and business-like: You may be asked to wipe your hand over the outside of your clothing in the area of your ostomy, and your hand will be checked for explosive residue. [You should not be asked to remove any clothing or expose your ostomy pouch](#) (link to TSA page on Ostomies).

TSA PreCheck ([TSA Pre✓](#)): As explained in [TSA's List of Travel Tips](#), the TSA Pre✓ program can expedite security screening by allowing you to keep shoes and belts on, avoid pulling out your 3-1-1 baggie, laptop, etc. And you may get sent through only a

metal detector instead of Advanced Imaging scanner, so you might not need to do the ostomy hand-swiping thing. To find out if you've been selected for TSA Pre✓ on a given flight, [examine your boarding pass](#) (whether hard-copy or mobile); if you see any of the notations "TSA PRE" or "TSA PRECHK" or "TSA Pre✓" then head to the TSA Pre✓ lane. Frequent flyer programs can improve your chance of selection, but make sure each program you belong to has [your full legal name](#), exactly as on your driver's license or other legal documents. Also, always use your full legal name when making airline reservations. The best way to improve your chance of selection is to enroll in a [Trusted Traveler Program](#), which gives you a "Known Traveler Number" (KTN). These programs have [application fees](#) and require you to provide certain documents, get fingerprinted and visit a [special enrollment center](#).

REAL ID Identification Requirements: By January 2018, depending on which state you live in, your driver's license may no longer be accepted as valid identification at US airports. That's because TSA will start enforcing provisions of the 2005 "REAL ID" law, as described in [signs that TSA is already posting in airports](#). The driver's licenses and other ID cards issued by some states aren't REAL ID compliant. As of January 22, 2018, TSA will accept such documents only if issued by a REAL ID compliant state or a non-compliant state with an extension. Based on current information, this means that residents of the following states will need an alternate form of ID, such as a passport, in order to fly after that date:

- Kentucky
- Maine
- Minnesota
- Missouri
- Montana
- Pennsylvania
- South Carolina
- Washington State

We will update this list as new information becomes available. You can also [check the status of your state's compliance](#), see all of the [forms of identification accepted by TSA](#), and see TSA's list of [frequently asked questions about REAL ID](#). You might also like to read a [Wikipedia page about REAL ID](#) for more background about that law.

All screening at airports must be conducted in a way that treats passengers with courtesy, dignity, and respect. You may request that any personal screening be conducted in a private area. If you have any questions or concerns about the screening process, you may call the [TSA Cares Help Line](#) at 855-787-2227. Also, see TSA's page on

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*Programming begins on August 23rd

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Conference Planning Underway

The UOAA National Conference Planning Committee met this month at the location of our next conference, set for 2017 in Irvine, California. Our 6th National Conference will be held at the [Hotel Irvine](#) August 22-26, 2017 with programming set to begin on August 23rd.

Committee leaders have been hard at work planning a schedule that builds on the success of the educational programming and fellowship of previous gatherings.

"As the speaker coordinator, I am excited about the great medical professionals from California who have agreed to present at this conference," says Mille Parker. She adds, "We have some great motivational speakers lined up and some returning favorites! As the sessions get finalized we will be highlighting them for you."



The committee includes local Orange County, California volunteers who will be working to staff the stoma clinic with dedicated nurses, build local enthusiasm, and help with the program organization. The ASG leadership academy and the exhibit hall will be there along with new educational sessions and special events. The committee also met with hotel representatives and are excited by the potential of the event space and the beautiful grounds and amenities of the hotel. It's not too early to save the date or start saving to attend what we think will be the event of the year for the ostomy community.

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I have a: Colostomy Ileostomy Urostomy (ileal diversion) Other Non-ostomate

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----- ✂ -----
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The Anniversary of my stoma is ____/____/____, and in order to celebrate my return to good health, I am contributing the sum of _____ or \$_____ per year for my stoma.

I hereby grant permission to print my name in the Chapter Newsletter.

Name _____ Years _____ Amount \$ _____

Send this form with your check, Payable to OAMA

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