UOAA United Ostomy Associations of America, Inc.
AFFILIATED SUPPORT GROUP

SPOKANE OSTOMY SUPPORT GROUP NEWSLETTER

Affiliated with United Ostomy Association of America, Inc.
Published Quarterly by Local # 349 (SOSG) - Editor: Phillip R. Moyle (SOSG.Input@gmail.com)
Issue 16 - 4 Advocates for Ostomates & Caregivers Fall 2016

CONTENTS

ENJOY THE HOLIDAY SEASON! ☺

MEETINGS & ANNOUNCEMENTS

Spokane Ostomy Support Group (SOSG)

Meetings for ostomates & caregivers are held on the first Tuesday each month (February-November) 6:30-8:00 p.m.

Providence Sacred Heart Medical Center
101 W 8th Ave, Spokane, WA 99204
Mother Joseph Room,
next to the cafeteria on L-3

*** Please contact Carol Nelson for questions and/or comments:**
call: 509-443-1242 or
email: *SOSG.Input@gmail.com*

All are welcome to join us!

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Upcoming Meetings & Topics

Oct. 4 - **Vendors – Ostomy Supply Reps.**
Nov. ~~8~~ 1 - **Nutrition Tips for the Holidays.**
Dec. / Jan.- **No meetings.**

Regional / National Events

*** 5K Runs for Resiliency: Boise, ID on October 8, and Portland on October 15, 2016; benefiting the UOAA.org.**

*** 6th National Conference, Irvine, CA 8 / 22-26 / 2017**

SUSIE & CAROL'S CORNER - WAZZUP

Expand SOSG Newsletter to Inland NW OSGs?

by Susie Leonard Weller

Happy Fall! As a retired teacher, September always feels like the beginning of a new year, ripe with possibilities. In a similar way, our newsletter is "upgrading!"

Additional ostomates who are living outside of the Spokane region are interested in receiving a copy, and perhaps contributing to our newsletter. As a result, Phil Moyle, our editor, Carol Nelson, Rich Judd and I, met to explore the possibility of expanding it to serve

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the Inland Northwest. We would focus on serving *all* ostomates living in Eastern Washington and North Idaho. This is the geographical area served by Rich Judd, an Account Manager for Byram Healthcare.

In particular, we'd like to reach out to the ostomates participating in support groups in Coeur d'Alene, Lewiston/Clarkston, Richland, Wenatchee, and possibly Yakima (see page 9). Ideally, we'd also collaborate with ostomy nurses and related health care professionals who want to provide an on-going resource for their ostomates. Kudos to Phil for his initiative, energy and computer skills to coordinate an outstanding newsletter! Another possibility is linking the newsletter to a website, and possibly an interactive blog, serving all of the ostomy support groups within our region.

Sherron West, an ostomate from the Coeur d'Alene group, graciously shared an example of a resource guide that she compiled for ostomates living near Sacramento, California. We'd like to partner with others to create a similar guide serving our Inland Northwest region. It could include a listing of all the support groups with the dates, times and locations of their meetings, medical resources, as well as local ostomy vendors and suppliers.

If so, let's consider changing the name of the newsletter and website to be more inclusive. Perhaps we could have a contest for a new name and logo? One option is: **I**nland **N**orthwest Ostomy Support—perhaps being known as the **IN**sider? Get your thinking caps on to brainstorm more possibilities. . .

In this issue you'll discover important information on how to pay for your ostomy supplies through Medicare or other heath care insurance. Pay attention to the enrollment deadlines this fall. Concerned about swimming with your ostomy? Discover practical tips for feeling confident in the pool. November often brings windstorms and power outages. Read about what to have available in your emergency kit for unexpected events.

On another note, **Arydyce Pangerl** was featured in the September/Fall 2016 issue of the *Phoenix Magazine*! Copies of her article were handed out at the September 5 Ostomy Support Group meeting in Spokane.

Ostomy Awareness Day is October 1, 2016. The United Ostomy Association of America (UOAA) is promoting the theme of **Resilience**. Several ***5K Run for Resilience Ostomy*** events will be held in various US cities, including Boise, ID (Oct. 8th) and Portland, OR (Oct. 15th). **Phil Moyle** will be participating in the October 8 "*5K Run for Resilience Ostomy*" in Boise, Idaho--he says he only walks and jogs!

Speaking of walking, I'm leaving on September 11 to hike a portion (about 71 miles) of the 500 mile Camino pilgrimage to Santiago de Compostela, in NW Spain. My husband and I won't be returning to the Northwest until mid-March. I'll be traveling with a 29 inch rolling duffel bag with just enough room to include my 45 liter back pack (about 21 pounds), trekking poles, travel gear (including a hernia belt and a stoma protector), and minimal clothes to make room for **90 colostomy bags and wafers!** I'll email you some details about our adventures throughout Europe, the East Coast of the US and Mexico. I know that you're in good hands with Carol facilitating the meetings while I'm gone.

Thanks to Rich Judd and Byram Healthcare for their assistance in publishing this newsletter. Contact Rich at rjudd@byramhealthcare.com to be added to the mailing list.

EDITOR'S NOTEs

(1) SOSG is collecting older issues of Phoenix, the official UOAA magazine, to compile a lending library for our ostomy community. So please let us know if you have older hard copies, or even digital (PDF) versions, of Phoenix. We are also compiling a list of important Phoenix articles as a reference library.

(2) We have corrected the telephone number for Carol Nelson, our current contact for SOSG and the Visitor Program: Carol Nelson at (509) 443-1242; carol@nelsonwheat.com.

(3) In the summer issue (16-3) of the SOSG Newsletter, the article "**How Many Ostomates Are There? *Statistics & Other Fun Facts*"** states "The Queen Mum had one too!" indicating that she was also an ostomate. However, Phil Moyle later found interview(s) with her surgeon, reported in British newspapers, denying that the Queen Mum had ostomy surgery. Lesson? Be careful with Internet reports!

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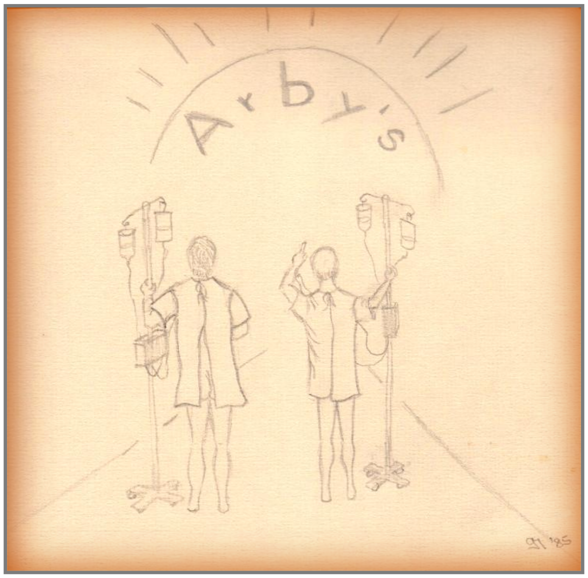
DIVERSION INSPIRATION & HUMOR

(*submissions & ideas welcome*)

You know you have an ostomy when...

When you hear someone talking about a "one piece" or a "two piece," you think of ostomy bags, not swimsuits. ☺

* **Phil's Short Story**: My wife Gisela drew this sketch in ⇨ September 1985 when my Holy Family Hospital roommate and I, both on a liquid-only diet, frequently threatened to escape so we could get some real food at the local Arby's. My ostomy surgery was performed about three weeks later, but I've always been inspired by the spirit we shared through "thick & thin," mostly thin! ☺



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NURSE'S CORNER - Q & A

Editor's Note: *In lieu* of our local professional ostomy nurses preparing the Nurse's Corner, this issue we offer an article which was "lifted" from another ostomy support group newsletter. Please make sure that you consult your ostomy nurse and/or physician before following any advice that is NOT submitted by our local ostomy nurses.

Not Everyone Knows

By Sharon Williams, RNET
(*via The Mail Pouch, Mesa, AZ May 2015*)

The experience of having a new ostomy can be quite frightening if one does not understand what is normal in stoma appearance and ostomy function and what is not normal. Although each ostomate is uniquely individual, there are some basic generalizations which can be cited in the postoperative period. For example, the normal, healthy stoma is bright red in appearance, resilient to the touch and may bleed slightly if rubbed when the peristomal skin is being cleansed. A marked change in stoma mucosa color or appearance should be reported to the physician or enterostomal therapist. Also, bleeding from inside the stoma (whether urinary or fecal) should signal a call to the physician for further testing.

It is normal for an individual with an ileal conduit or sigmoid conduit urinary diversion to have some mucus in the urine. Drinking sufficient amounts of water (8-10 glasses per day minimum) will help to keep the urine and mucus diluted.

It is normal for the skin surrounding the ostomy to be in the same condition as the skin on other portions of the abdomen. Redness, rashes, urine crystal buildup, etc., are not normal and should be reported to the enterostomal therapist or physician.

In individuals with colostomies and ileostomies who still have a rectum intact, it is normal to expel mucus through the rectum. The mucous membrane lining the rectum will continue to produce mucus, even though an individual is "re-routed." It is normal for the stoma to change slightly in shape and size due to peristalsis (contractile motion of the bowel which propels contents through the intestinal tract). However, marked swelling, prolapse, or shrinking in size of the stoma should be checked by a professional.

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It is normal for some colostomates and ileostomates to feel as though they still need to have a bowel movement (phantom rectal sensations) even though the rectum has been removed. The sympathetic nerves responsible for rectal control are not interrupted during surgery and therefore the sensations are still present. Knowledge of this fact may alleviate anxiety.

In summary, get to know your stoma and what is normal for you. Only by recognizing the norm can one know when and if a problem develops.

************************ "SEASONAL ARTICLE(S)" **********************

How Will You Pay for Your Ostomy Supplies?

Modified from UOAA *Articles to Share*, April 2016, by Julie Powell, WOCN

You’ve had your life-saving surgery, but how will you get and pay for your ostomy supplies? Depending on your age, Medicare or your healthcare insurance will pay for about 80% of your ostomy supplies.

Medicare is health insurance for people who are 65 or older. It also serves those who are under 65 with specific disabilities. Medicare has two parts: Part A is the Hospital Insurance; Part B is the Medical Insurance. **Ostomy supplies are covered under Durable Medical Goods in Medicare Part B.**

Your Medicare coverage will determine the following:

- Allowable fees for supplies - A yearly deductible is paid by the beneficiary (you, the ostomate). After the deductible is paid, Medicare Part B will cover 80% of the supplies; you are responsible for the remaining 20%.
- Allowable number of supplies -Medicare also determines **how many** ostomy supplies you can receive within a month. For example, a one piece drainable pouch for a fecal stoma has an allowable amount of **20 pouches per month**.

A physician’s order is required in the following circumstances:

1) The first time an order is placed for supplies.
2) When a yearly order is placed.
3) When an order is placed for an increase in the number of supplies, accompanied by medical justification for the additional supplies.
4) When there is a change in the type of supplies.

What if I don’t qualify for Medicare?

Individuals and children living in poverty can enroll at anytime in Medicaid or the Children’s Health Insurance Program (CHIP). There is no enrollment period for these programs, but there are income restrictions and other qualifiers.

Private healthcare insurance companies, as well as those covered through the Affordable Care Act, typically use the Medicare guidelines as their template for deciding what supplies they will cover. Contact your health insurance provider to clarify which ostomy supplies they will or won’t cover. Ask them to explain your out-of-pocket costs.

Unless there are special circumstances, such as changing or losing your job, you can’t make any changes to your existing healthcare plan except during the open enrollment period. Typically, the open enrollment period to change your coverage is from **November 1—December 15.** If you want any changes to your current health policy, pay attention to this deadline and make the necessary changes through your health insurer’s website.

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Got questions? For Washington State residents, call these numbers:

State Medical Assistance Office	Medicaid program	Toll Free: (800) 562-3022 (TTY now using 711 Washington Relay) Visit the Health Care Authority website (formerly - Department of Social and Health Services of Washington) at: **www.hca.wa.gov/**
1-800-MEDICARE	General Medicare information, ordering Medicare booklets, and information about health plans.	Toll Free: (800) 633-4227
SHIP -- State Health Insurance Assistance Program	Personalized health insurance counseling	Toll Free: (800) 562-6900 TTY: (360) 586-0241 Visit Statewide Health Insurance Benefits Advisors (SHIBA) website opens a new tabNew Window icon

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You know you have an ostomy when...

You don't have time to get any reading done on the loo - in 2 minutes, you're emptied and out of there!

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Swim Confidently with an Ostomy

Modified from UOAA *Articles to Share*, Summer 2016, by Ed Pfueller

Yes, you can safely go swimming with your ostomy!

After healing from surgery people of all ages and types of ostomies can and do enjoy swimming in community pools, athletic clubs, aquatic centers, oceans, and water parks. They also surf, swim and scuba dive* in open water, and relax in a hot tub.

But we understand the hesitation that some living with an ostomy may have. From worry of leaks to the reaction of fellow swimmers, the anxiety can be enough to keep some people out of the pool. There are no ostomy-specific restrictions to swimming in public places. Just follow all the normal pool rules, such as rinsing off before entering, just like everybody else.

Let's get you feeling confident in the water whether it is in your own backyard pool, the beach, or on a cruise. Here are some solutions to common concerns:

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I'm afraid that my pouch will leak or my wafer will loosen while I'm in the water.

If this is your number one concern, you are not alone. Remember, your pouching system is resistant to water and with a proper fit it is designed not to leak. If you have output concerns eat a few hours before swimming. A good practice is to empty your pouch before taking a dip. *If you are hesitant about how your wafer will hold, take a practice soak in your own bathtub.*

It is best to avoid applying a new wafer or flange and pouching system right before swimming. The WOCN Society recommends allowing 12 hours for proper adhesion. Using waterproof tape or water-specific barrier strips are not necessary for most, but can provide peace of mind. Be aware that some may have skin sensitivities to the adhesives in these products. There are a wide variety of ostomy supplies on the market for swimming, and you should be able to find a solution that works best for you.

Discover the optimal amount of time for you to stay in the water. Lynn Wolfson, a triathlete with Ostomy United suggests: "I limit myself to half an hour, forty minutes at most for maintaining the best adhesion.” Others find they can swim longer with no issues while some notice the need for an appliance change in a few hours or the next day after a swim.

If your pouch has a vent, another consideration is to make sure to use the provided sticker over the air hole so that the filter remains effective. When you have confidence with your ostomy pouch fit *out* of the water, you’ll feel more confident *in* the water. Remember, travel with your emergency kit of supplies wherever you go. (*see next article, "My Emergency Ostomy Kit"*)

What can I wear or do to help conceal my pouch and keep it secure?

Whatever your bathing suit style, wearing a patterned or darker color is less transparent than a light colored swim garment.

One-piece options for women include using a patterned design with a boy-leg bottom. For a two-piece suit consider a mix and match of tankini tops, high-waisted bottoms or boy shorts. You can also look for a suit with a concealing ruffle or skirt. The type of bathing suit depends on how many ostomies you have, where they are located on your abdomen, and what type of water activity you are doing.

Men often favor a higher cut waist for trunks, or suits with longer legs. Stretch fabric undergarments and swim or surf shirts also provide support. Also, consider using an ostomy band or wrap under your swim suit to hold the bag more firmly in place.

What do I do if I am approached by pool personnel concerned that my ostomy is an open wound or believe ostomy bags are not allowed in pools?

If you are approached by pool personnel who are uninformed about ostomies stay calm and try to educate them. However, no one should know you have an ostomy--unless you choose to tell them. If this is a recurring issue at your swimming location, review the resources developed by
UOAA Advocacy Manager, Jeanine Gleba, at:
http://www.ostomy.org/Swimming_with_an_Ostomy_Toolkit.html

The Americans with Disabilities Act ensures your right to access the pool. Most disagreements can be solved through education before exploring any legal recourse.

If you’re feeling modest about revealing your ostomy, you have options. When in the changing room, you could wear an oversized shirt or seek out a bath stall or a private corner. If asked about it, use this as a teachable

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moment. When Ostomy United founder Ted Vosk was training for an Ironman, this is how he handled some unsolicited comments. A guy pointed to his bag and said “I’m sorry you have that.” Ted replied: “You can feel sorry when you out swim me.” They both smiled because Ted had easily outperformed him in the pool.

So, get yourself a bathing suit and start swimming!

* ***Editor's Note***: I've done free (snorkel) diving as well as scuba and hookah (supplied air) diving both before and after becoming an ileostomate. One cautionary note is that intestinal gas accumulation in the pouch while diving to depth can expand when resurfacing. To reduce the chance of gas accumulation, I avoid eating for 3-4 hours and take an OFC gas-dampening medication (e.g. Beano) before a dive.

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My Emergency Ostomy Kit

Modified from UOAA *Articles to Share*, April 2016
By Christine Kim (ostomyconnection.com)

Winging It, Is NOT an Emergency Plan!!

Following my surgery, my ostomy nurse at the hospital gave me a starter kit and suggested that I keep extra supplies with me at all times. It was a little black carrying case that has pockets for various supplies. As a new ostomate I remember taking that starter kit with me everywhere, even on quick errands, because I was constantly afraid the ostomy bag would leak or fall off.

First Year After Ostomy Surgery

The first year was spent learning what worked, what didn't, and how to cope with the occasional accident. I remember feeling very anxious and was constantly making sure the pouch was secured and not leaking. It took some time to trust that the ostomy system would hold up, especially when doing any physical activity. Nights were spent sleeping on my back with my hand over the pouch. Nightmares of embarrassing leaks in public were common. There was so much anxiety about leakage that I decided to use a larger emergency kit with enough supplies for a week, along with extra clothes. But there were only a couple instances during that first year when I had an unexpected leak in a public place. I kept my wits and handled it as calmly as possible. Knowing that I had extra supplies gave me peace of mind.

Ostomy Living Now

These days I rarely check on my pouch. I've learned which foods cause higher output, how dehydration affects wafer adhesion, and what types of clothing constrict the stoma area. I've traveled far away from home, experienced different climate conditions, and stay very active. Though I am aware that it's there, my ileostomy is certainly not at the forefront of my mind.

If you're new to ostomy surgery, you might be feeling the same anxiety that I did in the beginning. I hope this gives you hope that any fears you may have are completely normal, but as time passes you'll gain more confidence and those worries will recede.

Be On the Safe Side

It has been over 20 years since my ileostomy surgery, and I still carry an emergency pack, the smaller one. I leave my house with confidence knowing I will be able to handle any situation. I don't expect an emergency, but I'm prepared if I have one.

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What's Inside an Ostomy Emergency Pack?

Here are some ideas:

- Ostomy pouches + clips (if using non-Velcro close).
- Ostomy wafers (pre-cut).
- Moldable rings or tube of stoma paste.
- Bottle of ostomy deodorizer (sample size).
- Barrier wipes (individual packets).
- Baby wipes or disinfecting wipes.
- Paper towel or wash rag(for clean up)
- Baggies
- Gauze Pads

Quick Tips:

1. Always store ostomy supplies in a cool, dry place.
2. Periodically cycle new replacement supplies, especially wafers and pouches, into the Ostomy Emergency Pack.

Editor's Note: This image and list (below) is of a recommended emergency ostomy travel kit. It was downloaded from *https://www.veganostomy.ca*.

1. Moist Towelettes (in ZipLock)
2. "Kitchen catcher" bags
3. Adhesive remover wipes
4. Ostomy pouch
5. Ostomy wafer
6. Hand wipes (sealed packs)
7. Ostomy gelling product
8. Gauze pads
9. Pen/marker to trace stoma
10. Medical/safety scissors
11. Barrier ring
12. Water
13. Compact mirror
14. Mini multi-tool
15. Medical tape (film)
16. Pouch deodorant
17. Cotton swabs
18. Resealable bags
19. Cellphone battery *
20. Stoma measuring guide
21. Keys *
22. Electrolyte powder
23. Wallet *
24. Headphones *
25. Business cards *

** Extra stuff in my kit

https://www.veganostomy.ca/my-ostomy-travel-kit-march-2015/

OSTOMY SUPPORT GROUPS IN EASTERN WASHINGTON & NORTHERN IDAHO

Coeur d'Alene Ostomy Support Group, ID:
Meetings are held from 6:30--9:00 p.m. on the 3rd Thursday of the month (February-November);
Kootenai Health & Medical Center, 2003 Kootenai Health Way, Coeur d'Alene, ID.
Classroom #2, near the cafeteria.
Contact: Shari Gabourie RN-CWON at (208) 625-6627 for more information.

Lewiston/Clarkston Ostomy Support Group, ID/WA:
Meetings, , , are held at 12:30 p.m. on the 2nd Monday in odd months;
St. Joseph Regional Medical Center, Wound Ostomy Continence & Foot Care Clinic
307 St. John's Way ,Suite12, Lewiston, ID.
Contacts: Jolene Tucker RN-CWOCN-CFCN & Samantha Musser RN-CWOCN-CFCN at (208) 799-5294.

Spokane Ostomy Support Group, WA:
Meetings are held from 6:30-8:00 p.m. on the first Tuesday each month (February-November);
Providence Sacred Heart Medical Center, 101 W 8th Ave, Spokane, WA.
Mother Joseph Room, next to the cafeteria on L-3.
Contact Carol Nelson at (509) 443-1242; carol@nelsonwheat.com.

Columbia Basin Ostomy Support Group, (TriCities), WA:
Meetings held quarterly from 12 noon to 2:00 p.m. (next meet on Thursday, October 13th;
Kadlec Healthplex. 1268 Lee Blvd, Richland WA in the Sycamore Room.
Contact: Wayne Pelly, our visitation Chairperson, at (509) 943-3223; wayne.pelly209@gmail.com;
or Lisa Bartholomew, RN, BSN, CWOCN at (509) 946-4611 Ext 5562; lisa.bartholomew@kadlec.org

Wenatchee Ostomy Support Group, WA: Information not available at this time.

Yakima Ostomy Support Group, WA: Information not available at this time.

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IMPORTANT SOSG SUPPORT CONTACTS

Providence Sacred Heart Outpatient Ostomy Clinic - M-F 8:00-2:30 (509-474-4950), leave a message if you don't reach someone live); appointments & MD referral required; No walk ins; Can be seen for follow up, checkup, questions, problems.

Deaconess Medical Center - Wound Center - M-F 9:00-3:00 (509- 473-7290); appointments & MD referral required.

Ostomy Visitor Program - Those who have had or are facing potential ostomy surgery should contact Carol Nelson (509-443-1242; carol@nelsonwheat.com) to arrange contact with or a visit from an experienced and trained ostomate Visitor.

Inland Northwest Bladder Cancer Support Group - A support group for urostomates and bladder cancer patients. Members meet the first Tuesday of the month at 5:00 p.m., Perkins Restaurant, on 12 E. Olive, in downtown Spokane. Contact Alan Roecks (509) 269-8026, or email him at BladderCancerGroup@gmail.com.

United Ostomy Association of America (UOAA) - (800-826-0826); P.O. Box 525, Kennebunk, ME 04043-0525; Link: http://www.ostomy.org/Home.html.

Phoenix Magazine - (800-750-9311); The Phoenix Magazine, P.O. Box 3605, Mission Viejo, CA 92690; Link: http://www.phoenixuoaa.org/ (get a free sample copy).

Primary Producers of Ostomy Products:

Hollister 1-888-808-74556	Coloplast 1-888-726-7872	Convatec 1-800-422-8811
http://www.hollister.com/	http://www.coloplast.us/Ostomy	http://www.convatec.com/ostomy/