Welcome Inland Northwest Ostomates!

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WHAZZ UP

The beautifully colorful shades of autumn are upon us once again, and with fall come many special occasions. Yes, the busy Christmas Holidays will announce the fall-winter transition, but let us not forget Hanukkah, Thanksgiving, Veterans Day, and a very special day important to our community – Ostomy Awareness Day! – October 6, 2018. Coincidently, October 6 also coincides with World Ostomy Day, celebrated every three years and sponsored by the International Ostomy Association. The theme this year is “Speaking Out Changes Lives!”

So let’s ask ourselves, “how can each of us ‘speak out’ in practical ways to make a difference, , ‘to change lives?’” How about something as simple as encouraging loved ones to get a colonoscopy screening by age 50--and perhaps earlier for those with a family member of colon cancer? Or some can speak out at work to access reasonable

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accommodations or more bathroom breaks as needed. What about educating store owners to allow those with an ostomy to use staff bathrooms as part of the disabilities act? Plus consider the importance of voting and speaking out to advocate on behalf of those needing affordable health care—especially with pre-existing conditions. I/we encourage all ostomates and their loved ones to become informed on the views of those running for political office and their position on topics affecting ostomates and to exercise their right and privilege to vote—one way of “speaking out to change lives!” For more examples, see advocacy tools and other ideas at https://www.ostomy.org/advocacy/.

The fall issue of “InSider” Newsletter includes reports of interesting regional events, especially the successful Youth Rally Fundraiser at the Northwest Regional WOCN Conference in September, and various ostomy support group activities. We include a feature about a YouTube video compiled by a recent ostomate who had sought help from the Coeur d’Alene Ostomy Association and subsequently underwent a successful reversal. In addition, announcement of an important upcoming event “Ostomy Education Day” on October 13 in Lewiston, ID. Articles include “Showering with an Ostomy” in our Nurse’s Corner and “Dementia Stoma Care.” Finally, please do not forget the upcoming Run for Resilience Ostomy 5k events in several US cities on October 6 and 13, 2018!

Check our updated regional website: inlandnwostomy.org. Visit the website to discover additional local, regional and national resources. Please note that we do incur annual domain and maintenance fees, so contact Phil Moyle if your support group would like to support our website and outreach efforts! Also, the newly revised UOAA national website at: www.ostomy.org is packed with new educational materials and great tips!

Please Remember that we at the “InSider” welcome your ideas and input! All ostomates, family & caregivers, and medical staff in our communities are welcome to submit articles, letters, and ideas! THANK YOU!

REGIONAL-OSG ACTIVITY REPORTS, ANNOUNCEMENTS, & LETTERS

Successful Youth Rally Fundraiser & WOCN Regional Conference

By Susie Leonard Weller, Spokane OSG

Imagine being a self-conscious teenager—and then add feeling lonely and different because you are coping with a significant bladder or colon medical challenge—without peer support. The goal of Youth Rally, a 5-day camp experience for those between 11-17 years old, is to let teens know: You are not alone! For the last 30 years, Youth Rally continues to be a “normalizing” community for young people meeting others who live with similar medical conditions. Lasting friendships are formed within five short nights, in an accepting atmosphere that promotes self-confidence, independence and leadership. Campers and counselors alike live with an array of conditions affecting their bowel and/or bladder systems.

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For many campers, this is the first time they have ever left home to spend time with their peers—including sharing a bathroom. Hunter Klein, a speaker at the September 21 Fundraiser in Spokane on the opening night of the Northwest Regional WOCN Conference, credits his two-year camp experience as smoothing his transition to group living in the dorms at Gonzaga University. He is studying to become a RN and wants to return to camp as a counselor next year. Lily Wright shared her story of being so inspired by camp and the WOCN RN’s who donate their time to staff it, that she wants to study to become a doctor. Eric Eng, attended his first camp as an 11-year-old. Since then, he has returned as a camp counselor for the last 12 years. These inspiring young people demonstrate “paying it forward.” In gratitude for the wonderful support they have received from their peers and medical professionals, they want to give back and to serve others.

Hearing their heart-warming stories encouraged 80 WOCN nurses and medical staff, 40 vendors, local ostomates and their loved ones to generously donate to the Youth Rally Camp. Phil & Gisela Moyle, Tom Theising and his friend Sheri Franks, Ival & Lang Seacrest, and Susie Leonard Weller represented the Spokane Ostomy Support Group. Michelle Best, a WOCN with the Providence Sacred Heart Wound & Ostomy Care Clinic, sat with the SOSG members. Michelle and another WOCN RN got the bid for multiple bags of home-made cookies and milk – what a treat for all at the table. According to Pamela Achabal, the WOCN Nurse in charge of the Youth Rally Fundraiser, the auction event raised $12,500—which is three times the money raised at past conferences!

Youth Rally camp rotates to different locations around the United States each year. However, the youth rally will be in Seattle July 8-13, 2019. Please encourage any teens you know with bladder or colon medical challenges, to apply to go to camp by visiting www.youthrally.org for more details.

Similar to the youth interacting with their peers, a highlight of the WOCN Regional Conference is the opportunity for WOCN nurses to network with their colleagues in six states: Washington, Idaho, Montana, Oregon and Alaska. Although it is not quite Halloween yet, ostomates benefit from WOCN’s sharing their Nightmares on Ostomy Street. This is where nurses share stories of what went wrong and how they are collectively learning to prevent these problems from happening again. This regional collaboration improves the quality of care for all ostomates!
Bethany “Faith” Hinshaw, an active 37-year-old woman from Coeur d’Alene, ID, underwent ostomy surgery (ileostomy) in June 2018 and had a successful reversal in August. Despite dealing with a variety of GI issues and additional medical conditions, she still managed to become a 3-sport varsity letterman in high school, and began competing in triathlons during her years of college where she majored in psychology and sociology with honors. Her health issues include intestinal abnormalities such as megacolon and pediatric ileum as well as a genetic predisposition for bipolar disorder and related mental health issues. Just as her life seemed to be turning around, Bethany faced two emergency surgeries this past May and June. She awoke surprised and a bit shocked after the surgery in June as she stared down at a stoma, something she never thought would happen. After the shock wore off, she definitely went through numerous challenges in learning to deal with an ostomy, as well as the grieving process in accepting it. Her initial summer plans were to get back to racing, but that took a definitive turn with the new ileostomy. "At first I felt defeated, I couldn't look at it," said Hinshaw, "so many mishaps occurred I would get so frustrated and mad." After going to a local ostomy support group and reading things online, she practiced a skill called "radical acceptance" and decided that this did not have to ruin her life, let alone her summer. "Amidst this struggle, I found resilience in myself that I never thought I had. Not only did I do things this summer I've wanted to do for a long time, it was probably one of the best summers I've had in years, despite the ileostomy,” said Hinshaw. She documented her activities with digital photos and videos, compiled a wonderful 16-minute video story titled “Finding Life again” using a free ‘app,’ and posted it on You Yube:  https://youtu.be/UCV5hCYXycQ. In June 2018, during the early part of her recovery, Bethany dropped in on a meeting of the Coeur d’Alene Ostomy Association. She was very impressed by the information and support she received according to a message that she sent September 18 to Sherron West, the group facilitator, just a few weeks after the ostomy reversal (extracts follow):

“I had a successful reversal a few weeks ago and wanted to thank the group for all the wonderful information and how courageous and amazing you are in living a life with an ostomy. I made a video of the summer to show that being an ostomate truly does not have to hold you back from fully living life and doing all the activities and fun things out there. I wanted to share the video with you as a thank you.” and “I think the next meeting is coming up, please share my thankfulness to the group and my blessings as they continue to deal with medical issues. Thanks so much again, , Bethany Hinshaw”

Bethany readily admits that she is not a “videographer” and that the audio is hard to hear. You have to admit though that she is certainly an athlete, and her courage and perseverance are very inspiring. Bethany’s “thank you” message to all ostomates and supporting family members includes her desire to give back to the ostomate community!

>Editor’s Note: The video credits include the statement: “SPECIAL THANKS, KMC Wound Care team & Ostomy Support Group” (KMC = Kootenai Medical Center in Coeur d’Alene, ID).
Lewiston-Clarkston Ostomy Support Group to Host

“Ostomy Education Day”

The Lewiston-Clarkston Ostomy Support Group (OSG) is going “All Out” to recognize and enhance Ostomy Awareness in our communities by hosting an “Ostomy Education Day” event in Lewiston, ID during October. Ostomy Education Day is an important outreach opportunity that will run from 9:00 AM to 3:00 PM on Saturday Oct. 13 in the Lewiston Community Center located at 1424 Main St., Lewiston, ID. It will include demonstrations, question and answer sessions with doctors and nurses, and vendors. What a great idea that can “Change Lives!” See announcement below.

**Ostomy Education Day**
Lewiston Community Center - 1424 Main St., Lewiston, ID
October 13, 2018 – 9:00 am to 3:00 pm

Speakers – Patient Stories - Demonstrations – Questions & Answers
Vendors – Samples - Videos – Goodie Bags – Free Lunch

**Presenters**
- Dr. Leroy Smith – “What is an Ostomy & Why? – Emergency vs Planned”
- Jolene Tucker, WOCN – “Types of Ostomies – Troubleshooting”
- Judy Reid, MS, WOCN – “How to Adapt to an Ostomy – Psycho-Social Adjustments for Patients & Caregivers”
- Tamara Youmans, WOCN – “Assessing Ostomy Site”
- Janet Sheelke & Adrian Wilson – “Changing your Ostomy Appliance”

**Vendors:** Byram Healthcare, Coloplast, Marlen, +?

**Registration - Contact:**
- Adrian Wilson – 509-243-4010
- Cheryl Hofer – 208-743-4088
- Janet Sheelke – 509-243-4615

**Suggested Donation:** $10.00

**Hosted by:** “Lewiston-Clarkston Ostomy Support Group”
(The Lewiston-Clarkston OSG meets the 2nd Monday each month from 12:30-1:30 PM at Tri-State Memorial Hospital located at 1221 Highland Ave, Clarkston, WA)

Falling down is a part of life; Getting back up is living!
Spokane Ostomy Support Group – Summer Activities

Members of the Spokane Ostomy Support Group remained active over the summer. We consumed a variety of “icy” desserts with tasty toppings thanks to Susie Weller, co-facilitator, during our Ice Cream Social on July 3. Our August support meeting focused on breakout sessions by surgery type, and in September, we held a “question & answer” session with WOCN nurse Michelle Best by having attendees submit confidential written questions. Michelle, with the Providence Sacred Heart Outpatient Ostomy Clinic, did a fantastic job of addressing all of our questions. See photo of Michelle (previous page) at the Youth Rally Fundraiser.

In early September three members of the Spokane Support group – Vicki Jo Henry, Phil Moyle, and Tom Theising - plus a couple of friends traveled over to the mountainous Idaho-Montana borderland to bike the Hiawatha Trail which follows 15 miles along an old railroad bed now converted to a graded bike route. The trail includes 10 train tunnels and 7 sky-high trestles with spectacular views. Trail bikers must pass through the 1.66-mile-long Taft Tunnel twice in order to return to the East Portal trailhead. Tom’s recumbent bike was not suited for the trail so he waited while Vicki Jo, Phil Moyle, and friends enjoyed completing the challenging 17-mile-long journey (see photos). Where will we go next year?

Photos of Vicki Jo Henry and Phil Moyle by tunnel (L) and on trestle (R) along the Hiawatha Trail, Idaho-Montana.

World Ostomy Day & Ostomy Awareness Day -

Saturday, Oct. 6, 2018 – will see the first of two weekends of Run for Resilience Ostomy 5k events in nine US cities:

> **Oct. 6, 2018** – Durham, NC; E. Stroudsburg, PA; Mesa/Phoenix, AZ; Birmingham, AL; Harrison Township, MI; Nashville, TN; Pennsauken, NJ; and Portland, OR; and

> **Oct. 13, 2018** - Boise, ID.
Run for Resilience events are sponsored annually by UOAA to raise awareness of this life-saving surgery, empower those living with an ostomy or continent diversion, and raise funds to support UOAA’s programs and services. If you are interested in participating in a Run for Resilience Ostomy 5k near our region – Portland, OR or Boise, ID – register as an individual participant or as a team by going to the following links:

- **4th Annual Portland, OR Run for Resilience Ostomy 5K** (October 6) - [https://www.ostomy.org/event/4th-annual-portland-or-run-for-resilience-ostomy-5k/](https://www.ostomy.org/event/4th-annual-portland-or-run-for-resilience-ostomy-5k/)
- **3rd Annual Boise, ID Run for Resilience Ostomy 5K** (October 13) - [https://www.ostomy.org/event/3rd-annual-boise-id-run-for-resilience-ostomy-5k/](https://www.ostomy.org/event/3rd-annual-boise-id-run-for-resilience-ostomy-5k/)

Alternatively, if you are interested in participating in the Run for Resilience Ostomy 5k but are unable to physically attend the live events, try a virtual run:

- **Virtual Run for Resilience Ostomy 5K** (October 6) – [https://www.ostomy.org/event/virtual-run-for-resilience-ostomy-5k/](https://www.ostomy.org/event/virtual-run-for-resilience-ostomy-5k/)

Participants may also sign up to be a Fund Raiser. Phil Moyle, a Spokane OSG member as well as a regular participant in the Boise Run for Resilience Ostomy 5k, signed up as a Fund Raiser for the 2018 event by seeking sponsors ([https://runsignup.com/PHILMOYLE-SPokane](https://runsignup.com/PHILMOYLE-SPokane)). Phil also challenges other ostomates, family members, and members of our regional ostomy community, including medical staff and suppliers, to sign up as participants and Fund Raisers! For more information on the Boise event and the organizers, the Herrett family, please go to the UOAA website at [https://www.ostomy.org/herrett-family-story/](https://www.ostomy.org/herrett-family-story/) and/or check out the January 2017 issue (17-1) of the Inland Northwest Ostomy Support Groups “Insider” Newsletter: at [http://inlandnorthwestosg.com/Newsletters/Insider/Insider-2017-1%20Winter.pdf](http://inlandnorthwestosg.com/Newsletters/Insider/Insider-2017-1%20Winter.pdf).

************************** NURSE'S CORNER **************************

*Editor's Note:* We invite ostomates in our Inland NW community to submit suggestions on subjects for us to cover and to ostomy nurses on how to better deal with ostomates during examinations. Please send your ideas to [SOSG.Input@gmail.com](mailto:SOSG.Input@gmail.com).

**“Showering with an Ostomy”**

From UOAA Articles to Share 6/1/2018 - Ask Nurse Brown, CWOCN

Dear Nurse Brown,

I really enjoy a long, hot shower. The problem is my pouch gets wet and then takes too long to dry. Is there a way to keep my pouch dry in the shower? W.R.

Dear W.R.,

There are many products on the market to cover your pouch, but with a long, hot shower, even the steam will dampen the pouch. Have you tried drying your pouch and wafer using a hair dryer on a cool setting? You can also fold your empty pouch up during the shower and secure it with a clip or large bobby pin. This can limit the amount of the pouch that gets wet and then towel dry or use the hair dryer. Some ostomates that use a two-piece system keep a “shower pouch” that they only use during showers, replacing it with the pouch they were going to wear, and allowing the wet pouch to dry until the next shower.

> **Editors Note:** Please consult with an ostomy nurse with additional questions regarding these issues.
Caring for an ostomy can often be a frustrating and challenging experience at any age. But combine advanced age and dementia and it becomes even more of a challenge for caregivers and loved ones. According to the Population Reference Bureau, the number of Americans 65 and older will gradually increase from 15% of our population to 24% by 2050. With this growth has come a rise in existing and new ostomies combined with Alzheimer’s or other dementias. The Alzheimer’s Association of America (www.alz.org) reports in their 2017 Alzheimer’s Disease Facts and Figures report, “Of the estimated 5.5 million Americans with Alzheimer’s dementia in 2017, 5.3 million are age 65 and older.” The association predicts a half a million new cases of Alzheimer’s dementia will develop annually.

This explosive growth in new cases of dementia is putting an enormous strain on family caregivers. The Family Caregiver Alliance (www.caregiver.org) estimates, “44 million Americans age 18 and older provide unpaid assistance and support to older people and adults with disabilities who live in the community.” These caregivers often have little or no preparation or support in providing care for people with disabilities such as stoma care. They become frustrated and worn out. In an online forum, an anonymous writer expressed her frustration about caring for her mother’s stoma as follows, “I am TIRED of it. I need someone to take over dealing with an ostomy and ordering the correct supplies for her, etc... And I am just going to make whatever decisions seem right regarding her bladder care, as I find out more info. I really wanted to yell at her tonight and that makes me feel like a terrible, awful person. I didn’t, but I did get a little firm.”

Studies have shown that family caregivers who provide care to family members with chronic and disabling conditions are also putting themselves at risk of developing emotional and physical health problems. When seeking stoma care information, caregivers often participate in online chat rooms and forums for anecdotal advice. Additionally, visiting nurses with wound and ostomy training often make home visits and teach ostomy care. However, when they leave, the caregiver is often faced with ever-changing challenges as their loved one’s dementia worsens. Most often, they face the challenge of not knowing when a pouch needs to be emptied, appliances being ripped off by their loved one or attempts to empty and change the appliance that miss the mark and require massive cleanups.

Realizing the complexity of stoma care and dementia and the pressure it causes to caregivers, the Colostomy Association of the United Kingdom and the Dementia Association of the United Kingdom combined to issue a twelve-page downloadable leaflet at www.dementiauk.org entitled, “Caring for a person with a stoma and dementia.” They readily recognize that not all persons with dementia will profit from learning to care for their stoma. But where it is possible a person should be encouraged to participate in their own stoma maintenance.

The leaflet’s content is based on input from health professionals who care for ostomates with dementia and a stoma. A few of the hints and tips included in the publication are:

- “People with dementia who are actively involved in changing their bags should be encouraged to wear gloves. This reduces the risk of infection, feces under the nails and fecal spreading.”

- “Some people with dementia who require their bag to be changed for them might resist. In these cases distraction could help. For instance, encouraging the person to clean their teeth or brush their hair during
the process might be helpful. Standing the person in front of a mirror so they can focus on the task they are performing and not the bag change can help.”

- “Bag choice is important. One-piece bags with pre-cut aperture have the advantage of being uncomplicated for both person and caregiver. Two-piece bags, where the flange can remain in situ for up to three days, help protect the skin where frequent changes are necessary.”

Individual and professional caregivers also provide additional advice based on their experiences. Many staff who work in nursing homes put a plastic bag over the pouch so that in case of any leakage, there won’t be a much larger incident. Many persons with Alzheimer’s or other dementias either pick or rip off their pouches. To prevent this from happening, many caregivers dress their loved ones in special clothing that has no openings in the front but still gives the appearance of normal clothing. One source for this type of clothing is Buck and Buck. Their online catalogue features adaptive clothing by gender and condition.

Lastly, in this Smartphone age there is even an app that might help. 11 Health has created the Alfred Alert Sensor. The sensor is applied to the pouch at a point where it should be emptied. When that point is reached, it connects by Bluetooth wireless technology to the Alfred Alert app on your Smartphone to tell you it is time to empty. The app can also capture patient output volume over a period of time. The data is stored in a HIPAA compliant cloud server where it can be shared by medical professionals and family members.

In the final analysis, caring for a loved one with dementia is a joint effort between the person with dementia, their loved ones, their medical consultants and other professional caregivers.

The STRUGGLE you are in Today Develops the STRENGTH that you need for Tomorrow!

IMPORTANT SUPPORT CONTACTS & LINKS

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.

Spokane Ostomy Visitor Program - Those who have an ostomy or face 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 Keith Alloway (509) 847-5999, or email him at KI.alloway@comcast.net.

Ostomy Clinic in Lewis-Clark Valley - Tri-State Wound Healing (Ostomy Clinic), Clarkston, WA – Call 509-758-1119 – referral not required.

United Ostomy Associations 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
OSTOMY SUPPORT GROUPS & MEETINGS*
EASTERN WASHINGTON & NORTHERN IDAHO

(We recommend that you call the support group contacts to verify meeting times, agendas, & locations)
(Also, check the “Inland Northwest Ostomy Support” website: http://inlandnwostomy.org)

Coeur d'Alene Ostomy Association, ID (# 409):
- Meetings held from 6:30—8:30 pm on the 3rd Thursday of each month (February-November);
- Kootenai Health & Medical Center, 2003 Kootenai Health Way, Coeur d'Alene, ID.
  Heart Center Classroom, 3rd floor, south wing above ER.
- Contacts: Shari Gabourie RN, BSN, CWON at 208-625-6627 or Sherron West, CDA OSG President, at 208-719-0776 for more information.

Lewiston-Clarkston Ostomy Support Group, WA/ID (# 134):
- Meetings held at 12:30-1:30 pm on the 2nd Monday each month (January-December);
- Tri-State Memorial Hospital, 1221 Highland Ave, Clarkston, WA; hospital conference room on main floor.
- Contact: Janet Scheelke, President at 208-305-1723.

Spokane Ostomy Support Group, WA (# 349):
- Meetings held from 6:30-8:00 pm on the first Tuesday each month (February-November);
- Providence Sacred Heart Medical Center, 101 W 8th Ave, Spokane, WA. In 2018, we will meet in the Avista A & B Room in the SHMC Women’s Center (west end of complex).
- Contacts: Susie Leonard Weller at 509-499-1423 or Carol Nelson (Visitation Program) at 509-443-1242.

Mid-Columbia (Richland) Ostomy Support Group, (TriCities), WA (# 278):
- Meetings currently held January & March at 12:00-1:30 pm, May & September at 4:30-6:00 pm, and November at 12:00-1:30 pm (https://education.kadlec.org/registration/11-wellness/94-support-group-ostomy).
- Kadlec Healthplex, 1268 Lee Blvd, or main Kadlec Campus 888 Swift Blvd. Richland WA; room varies.
- Contacts: Lisa Bartholomew, RN, BSN, CWOCN at 509-946-4611 Ext 5562; or Wayne Pelly (Visitation Chairperson) at 509-943-3223.

Confluence Health (Wenatchee) Ostomy Support Group, WA (# 398):
- Meetings held quarterly at 2:00 to 4:00 pm (see contacts for meeting schedules and agendas.
- Confluence Health Central Washington Hospital 1201 S. Miller St., Wenatchee, WA; Conference rooms F & G.
- Contact: Tyree Fender, RN, BSN, CWOCN at 509-665-6156.

Yakima Ostomy Support Group, WA:
- Meetings held bimonthly at 10:00 to 11:00 am, generally on the third Wednesday of January, March, May, September, & November (check with the inpatient Wound/Ostomy Care Department for details);
- Virginia Mason Memorial, 2811 Tieton Drive, Yakima, WA, usually in basement – Classroom C;
- Contacts: Virginia Mason Memorial Ostomy/Wound Care Services – Karen Aal, RN, MS, CWON; Lois Engel, RN; or Allyson Uhlman, RN, CWOCN, at 509-575-8266.

* Editor’s Note: Please let us know if errors need to be corrected or changes made to the information reported above (SOSG.Input@gmail.com).