INLAND NORTHWEST OSTOMY SUPPORT GROUPS

"Insider" Newsletter

Published Quarterly - Editor: Phillip R. Moyle (SOSG.Input@gmail.com)

Issue 17 – 2 http://inlandnwostomy.org Spring 2017

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WHAZZ UP

Spring Blossoms New Connections

by Susie Leonard Weller

WELCOME to the second issue of the "***InSider***" Newsletter! Thanks to the efforts of Phil Moyle, our newsletter editor and Rich Judd from Byram Healthcare, we are developing new relationships with ostomates throughout the Inland Northwest. You will notice more emphasis on this being a REGIONAL newsletter serving the following Ostomy Support Groups:

- Coeur d'Alene Ostomy Association, ID;
- Lewis-Clark United Ostomy Association, ID/WA;
- Spokane Ostomy Support Group, WA;
- Mid-Columbia (Richland) Ostomy Support Group, WA;
- Confluence Health Ostomy Support Group, Wenatchee, WA; and
- Yakima Ostomy Support Group, WA.

I hope that you have checked out our new website, "**Inland Northwest Ostomy Support**" (INWOS), at ***inlandnwostomy.org***. Although it also links to an additional website at ***inlandnorthwestosg.com***, we are in the process of fixing that later this year. Please let us know if we need to make corrections or to include additional information.

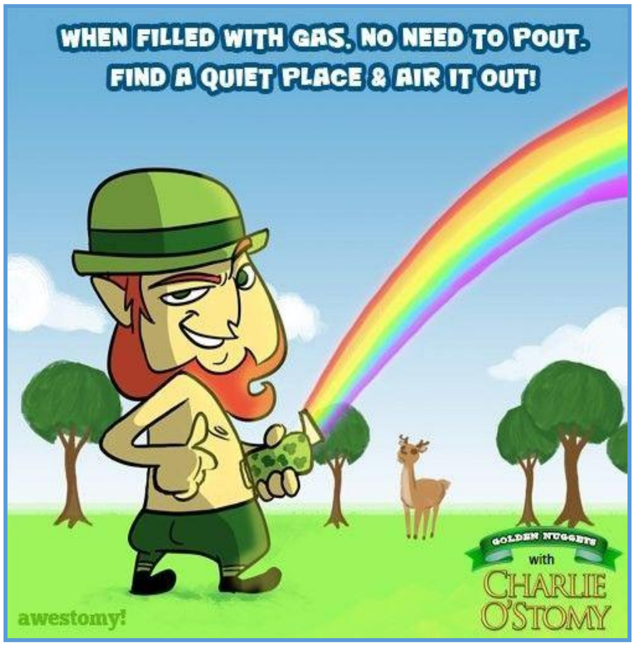
In this newsletter, you will also discover the following resources:

- Learn about the Yakima, WA and Coeur D'Alene, ID Ostomy Support Groups;
- See what you missed at recent Spokane OSG meetings;
- How to handle the "hairy" problem of *folliculitis*;
- Why advocating for yourself and other ostomates is so vitally important;
- Understand the history of the UOA (United Ostomy Association) and its successor the UOAA (United Ostomy Associations of America);
- Information about the National Ostomy Conference in Irvine, CA this August;
- Tips for coping with chronic pain.

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.

DIVERSION INSPIRATION & HUMOR

(*Submissions & ideas welcome*)



***************** REGIONAL OSG ACTIVITIES REPORT ******************

Snapshot of the "Yakima Ostomy Support Group," Washington

By Karen Aal, RN CWOCN,
Virginia Mason Memorial Wound Care Services, Yakima, WA

The **Yakima Ostomy Support Group** began at the Yakima Valley Memorial Hospital in the 1980's by two 'Enterostomal Therapy' nurses (as they were called then). Lillian Hamilton and Karen Aal, shortly after completing 'ET 'school together at St. Paul's Hospital in Vancouver, British Columbia, Canada started the support group. Karen is still a nurse at the hospital, now named **Virginia Mason Memorial**, and she is the lead person for the support group. Although they originally met in the evenings, the group changed the meeting times to accommodate the needs of the older members who found it easier to meet during the day. The Yakima OSG is generally a small but passionate group that meets and provides support to each other. For people who are not able to attend meetings, or prefer one-on-one support, experienced ostomates make phone contact or visit in person, after the 'newbie' has returned home.

Generally about 6-10 people attend the support meetings which are held from 10:00-11:00 a.m. on the third Tuesday in January, March, May, September, and November. The meetings are held at in the basement in Classroom C at Virginia Mason Memorial, 2811 Tieton Drive in Yakima. If there is a change in location, will staff posts signs.

Please call Karen Aal, Allyson Uhlman, or Lois Engel at Virginia Mason Memorial Wound Care Services for more information at (509-575-8266). All are welcome to attend meetings.

History of the "CDA Ostomy Association" Support Group, Idaho

By Sharon Gabourie RN,BSN, CWON, Kootenai Health & Medical Center,
Coeur D'Alene, ID, with assistance from Sherron West, President

In 1988 Sharon Gabourie began her career with Kootenai Health as the Enterostomal Therapy Nurse Assistant for Dorothy Thielman. Dorothy was Kootenai Health's first ET nurse starting in 1979 or 80. Dr. Timothy Quinn was responsible for getting this position started, realizing the need for ostomy education and support for local patients. He was responsible for Dorothy's return to school to become an ET nurse. Dorothy was very active in the regional and national nurse society holding several different officer positions over the next few years. She later became Director of Risk Management at Kootenai Health but continued to be active in WOCN. She has since retired.

Dorothy began the Ostomy Support Group in the mid 1980's. In 1988 Sharon Gabourie was hired as the ET Nurse Assistant and became an active participant with the group. Harold Derting was the president of the group and for the next 10 years meetings were held monthly. By the year 2000, with dwindling membership and the passing of Harold Derting, the support group disbanded. Sharon went back to school for her BSN and Ostomy /Wound Certification. In May 2016, Sharon Gabourie RN,BSN, CWON, with inspiration from Sherron West to rekindle the group and the help and support of the Wound Care Department, founded the "**CDA Ostomy Association" support group**.

Meetings are held the Third Thursday of each month with the exception of December and January from 6:30 to 9pm, Rm. 2, next to the Cafeteria. We wish to "Thank" Kootenai Health for graciously allowing our meetings to be held at the hospital.

"Coloplast Representative at SOSG February Meeting"

Vince Faiola, Coloplast Ostomy Territory Manager, came all the way from Portland, OR, to give a lively presentation to SOSG members who attended the February 7th 2017 meeting at Sacred Heart Medical Center in Spokane, WA. In the accompanying photo, Vince wears a stoma display belt to demonstrate various Coloplast appliances while Carol Nelson holds graphic displays on the wall. Four years with Coloplast, Vince has a passion for helping the ostomy community and working with WOC Nurses to improve quality of life. WOCN named Vince the Pacific Coast Regional Representative of the Year in California last year.

"Nutritionist Offers Advice at SOSG March Meeting"

Ashley McNutt, a Registered Dietitian at Providence SHMC, offered excellent advice on nutrition, especially vitamin & mineral supplements for ostomates, including where in the intestines nutrients are absorbed. Emphasis was placed on a balanced diet (*see **ChooseMyPlate.gov** that replaces the food pyramid*) with advice to: chew food well; eat small, frequent meals; largest meal at lunch; and drink plenty of fluids! The subject stimulated a great exchange of experiences and ideas: *What works for some may not necessarily work for others!* All of those who attended left well informed. **Thank You Ashley!!**

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

Editor's Note: *In lieu of our local professional ostomy nurses preparing the Nurse's Corner, we offer an article that was "lifted" from another OSG newsletter. Please consult your ostomy nurse and/or physician before following any advice that has NOT been reviewed and approved by your local ostomy nurses.*
*** Please let us know of subjects that you would like presented in this column!*

FOLLICULITIS—A Hairy Problem*

By Kathy Dahn, RN, Riverside Health Care, Edited by B. Brewer, 12/2011 UOAA Update.
Source: Regina Ostomy News May/June 2013

This is an article about an annoying peristomal skin condition, folliculitis. This issue primarily applies to hairy men, as women seldom have much hair on their bellies. In fact, abdominal wall hair can be so strong that it can grow out through a skin barrier or waterproof barrier tape sticking straight up like blades of grass. If I had not seen this myself, I would never have believed it. Needless to say, when you remove the skin barrier and the hair is caught like this, it is going to be painful. It is like those wax jobs you see on TV.

As if the pain is not enough, this type of hair removal can cause folliculitis, which is an inflammation within the hair follicle. Removing the skin barrier in a rough manner and dry shaving can also cause folliculitis. This condition presents itself as reddened bumps on the peristomal skin. This redness may be confused with yeast infection. However, if you look carefully, the redness is only present in the hair follicle. The bump may look like a pustule. What is the solution to this hairy problem?

Many men find they must shave the peristomal skin with each change of their skin barrier. In the past, the ostomy literature has always recommended using an electric razor. I personally have never had great success

Continued on next page

with this method, although I have heard that some folks do very well with the newer small razors that were designed for trimming mustaches and sideburns. If you use a safety razor, as we do in the hospital, be sure to apply sufficient shave cream so that this is not a dry shave. In addition, be gentle.

Most shave creams have emollients so you will need to wash the skin very lightly with a plain soap afterwards. Be sure to rinse your peristomal skin will so that no soap residue remains. If the skin is very irritated and itchy, we have found Kenalog spray or Desonide lotion is extremely helpful. This is a steroid (cortisone) solution, which decreases the itching and irritation dramatically. Apply these lightly, and then allow drying completely prior to putting on your new skin barrier. These medications have a slightly oily base, which means your skin barrier probably will not stay on as long as you are accustomed. This procedure will relieve the itching and promote healing.

Skin heals better covered by a skin barrier than it would if aired out. Do not use any steroidal spray as part of your regular changing routine. Steroids are absorbed into your system through the skin. Moreover, steroids will thin the skin, compounding peristomal skin issues.

If there are actual pustules around each hair follicle, you may need to use an antibiotic powder such as Polysporin powder to clear the problem. All the products mentioned above require a prescription to obtain. Folliculitis is not as common a concern as skin breakdown or yeast infection, but it is very annoying when it happens. End

***Editors Note**: Please consult with an ostomy nurse regarding this issue and suggested treatment.*

********************** **QUARTERLY ARTICLE(S)** *******************

"Be an Advocate for Yourself and All Ostomates"

By Phillip Moyle, SOSG

Healthcare is one of the biggest issues in daily news headlines these days. While our elected officials are pondering ways to change our healthcare system, it is important to educate them about the medical needs of 900,000 ostomates living in the United States.

On March 10, 2017, I went to Capitol Hill in Washington, D.C. to let my members of Congress know about my life as an ostomate and how their decisions can help to maintain my healthy life or cause harm to me and possibly all ostomates. With the assistance of the UOAA and some of our own members, I drafted a letter and assembled educational materials & issue papers which I presented to staffers during meetings at the offices of Senator Patty Murray, Senator Maria Cantwell (*see photo*), and Congresswoman Cathy McMorris Rodgers. All of the meetings were friendly and productive!!

Do you have to go to Washington to make a difference? Absolutely not! The United Ostomy Associations of America (UOAA) is the leading organization proactively advocating for people living with an ostomy or continent diversion.

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Phil Moyle (L) and Nico Janssen (R), Staff Assistant to Senator Maria Cantwell, 3/10/2017

You can be an advocate too! All you have to do is care enough to take some kind of action. . To make it easy for you, we are adding an "*advocacy page*" to our website that has a link to the UOAA advocacy webpage (http://www.ostomy.org/Advocacy_Action.html, *see the image below*). It is important that you exercise your democratic right and responsibility to let your elected officials know how you feel! Just try it. If you have a problem, feel free to call or email Jeanine Gleba, the Advocacy Director for UOAA (1-800-826-0826; advocacy@ostomy.org). . **End**

UOAA Advocacy – Take Action!

Every voice counts.
And every person living with an ostomy should be heard.

Advocacy is promoting what is important to you, and persuading others to support your cause. The most convincing advocate for UOAA is the individual who can talk about a personal experience with their ostomy surgery. No one knows better than you what living with an ostomy is like. You can make a real impact on decision-makers and together we can drive change.

Because none of us is as loud as all of us.

Advocacy Agenda | Share Your Access Story

Take Action: Support Critical Patient Protections During the Current Healthcare Reform Effort

Take Action

&

Make a Difference!

"A Brief History of the UOA & UOAA"

(Condensed by Phillip Moyle and compiled from resources by Bobbie Brewer and others)

Have you ever wondered about the history of the United Ostomy Associations of America (UOAA) and its predecessor, the United Ostomy Association (UOA)? The UOA formally began with a "Constituting Convention" held in Cleveland, Ohio in 1962, but it didn't just happen overnight! According to an informal history (author unknown but probably Bobbie Brewer from Atlanta), groundwork for the eventual UOA unification ", , *began as early as 1949 when ostomy patients began to meet together for support*, , ,." at a Veterans Hospital in Valley Forge, Pennsylvania! My guess is that many of these patients were WWII survivors. Additional groups (chapters) formed through the 1950s, and eventually cooperative efforts by chapter representatives led to incorporation of the UOA in 1962 with 28 affiliated groups.

The Los Angeles-based organization grew steadily through the 1960s, adding an "Ostomy Quarterly" magazine; adopting the Phoenix (see *Editor's Note* below) as the official logo. By the late 1970s, UOA membership reflected 554 affiliated chapters and approximately 40,458 members. Dues had increased from 50 cents to $4 per year. The 1980s saw continued membership growth and expansion of outreach activities. The first UOA woman president, Bobbie Brewer, was elected in 1982. When I became an ostomate in 1985, the UOA was a very well established and active organization still in an expansion mode.

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By 1988, the nurses managing the care of ostomy patients began to be more specialized. Their preferred name became Enterostomal Therapy (ET) Nurses. In 1989, the UOA began adding celebrities to its membership as honorary members; these included San Diego Chargers placekicker Rolf Benirschke, and Marvin Bush (son of President George Bush).

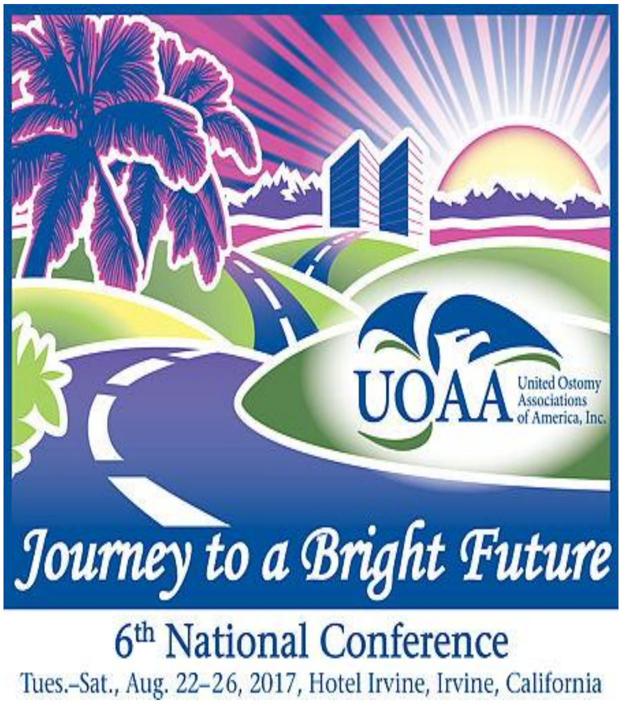
The ambitious growth of the UOA apparently peaked around the early1990s. From 1991 to 2001, membership declined from approximately 43,000, representing 625 chapters, down to about 25,000 members with only 450 chapters. Finally, on September 30, 2005, the UOA ceased operations permanently due to "a declining member and donor base, inadequate financial support, and increasing operating costs. In addition, local chapters were disbanding rapidly and it was difficult to maintain a supply of leaders at all levels. For more details, visit the historical archive website a thttp://web.archive.org/web/20051115030124/http:/www.uoa.org/.

Later in 2005, the United Ostomy Associations of America (UOAA) became the successor to the UOA. Membership in UOAA opened to any former UOA chapter, or support group, such as those that formed by a medical professional, hospital, or allied agency that chooses to affiliate. Rather than individual membership, the UOAA offers affiliations to local groups each of which is assigned an Associated Support Group (ASG) number. There are currently (2017) over 300 ASG's. Now in its 12th year, the organizational hierarchy of the UOAA is much leaner than the previous UOA. Instead of the numerous regional conventions and an annual convention that characterized the UOA, the current organization holds just one National Conference every other year. The *Phoenix Magazine* remains the official publication of the UOAA.

The primary communication and outreach tools have become their website (http://www.ostomy.org/Home.html) and regular newsletters. The UOAA also holds 5-k *Runs for Resilience* in various cities around the U.S. These runs are held annually on the first Saturday of October. They coincide with **National Ostomy Awareness Day,** which began in 2010.

A local ASG facilitator, Susie Leonard Weller, will attend and present at the 6th UOAA National Conference this year, August 22-26 in Irvine, California. Call the UOAA at 1-800-826-0826 or check out the UOAA website http://www.ostomy.org/2017_National_Conference_Page.html if you are interested in joining Susie at what promises to be a very exciting event!

***Editor's Note**: In Greek mythology, a **phoenix** is a long-lived bird that is cyclically regenerated or reborn. Associated with the Sun, a **phoenix** obtains new life by arising from the ashes of its predecessor. A fitting symbol!!.* End



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"Plan for the future because that's where you're going to spend the rest of your life"
– Mark Twain

"Coping With Chronic Pain"

(*UOAA Articles to Share, 2016 summer*)

By Lynn Wolfson, Broward Ostomy Association (near Ft. Lauderdale, Florida)

***Editor's Note**: Lynn was born with Hirschsprung's Disease that severely affects the digestive system, and she has had over 30 surgeries since she was 4 years old. At this time, she has her seventh ostomy, a gastric tube for stomach venting since she is unable to vomit, a Jejunal tube for feeding due to severe motility issues, difficulty breaking down of foods and malabsorption of nutrients. In addition, she has a neurogenic bladder (a flaccid or spastic bladder caused by neurologic damage) She needs to catheterize it two to three times a day. Lynn enjoys traveling the world with her family.*

Chronic pain is something that most people with digestive diseases live with on a daily basis. Learning to cope with this pain and to live a productive and meaningful life can be a tremendous challenge. However, with the appropriate support, attitude, exercise and diversions it can be managed. However, this is not easy to learn and is very individualized. It is very important that a person with chronic pain surround themselves with people that are positive and supportive. These people are the ones that you want to see on a regular basis. This may include family, friends, book clubs, card groups, synagogue or church groups or any other group that meets on a regular basis. Talk to these people and get to know them. Listen to their challenges and give creative positive solutions. I find that when I am helping another individual, I forget about my own ailments for the moment. I put my feet in their shoes and look at life with a completely new perspective.

Attitude is another important characteristic. Unfortunately, for most of us, this chronic pain is here to stay. Accept it. Try to understand the difference from chronic pain and acute pain. Make a list of the things you have done in the past that have helped. I keep this list on my phone. My list includes venting my gastric bag, catheterizing, lying down, pushing my hernia back in place, making sure my ostomy is outputting a sufficient amount, stop eating, and feeling for any hardness in my abdomen. If I find that my output is very low or I feel a hardness in my abdomen, I know to call the doctor.

I find exercising on a regular basis keeps me healthy and happy. For me, I swim 30 laps three to five times a week at the YMCA. I also walk around my neighborhood. Perhaps there are other exercises which you are capable of doing and can enjoy.

Lastly are "distractions." For me, I enjoy knitting hats. I find that by keeping my hands moving and my mind focused on my hands, it helps me to endure the pain. I consider knitting turning the negative energy of pain into positive of energy of giving a hat to someone in need. Perhaps others would enjoy doing a puzzle or building a model or painting or needle point. I also find playing scrabble or Words with Friends on the computer another diversion. It took me a while to figure out what works for me. Try to learn what causes your pain or when your pain is at its worst. I find I am in pain after eating or standing or sitting too long. Once I realized that, I adjusted what I was doing.

Coping with chronic pain is a challenge. However, once I gained control and understood my pain, I found I started to enjoy life. We have all been given the gift of life. However, no one's gift was free of flaws. Accept our strengths and use them to create a meaningful and productive life.

A book that has significantly helped me is entitled "*The Pain Survival Guide, How to Reclaim your Life*," by Dennis C. Turk, PhD., and Frits Winter, PhD., published by the American Psychological Association. The book covers the themes of becoming your own pain manager expert with sections on activity levels, rest and pacing; relaxation; fatigue; relationships; thoughts; and feelings. End

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

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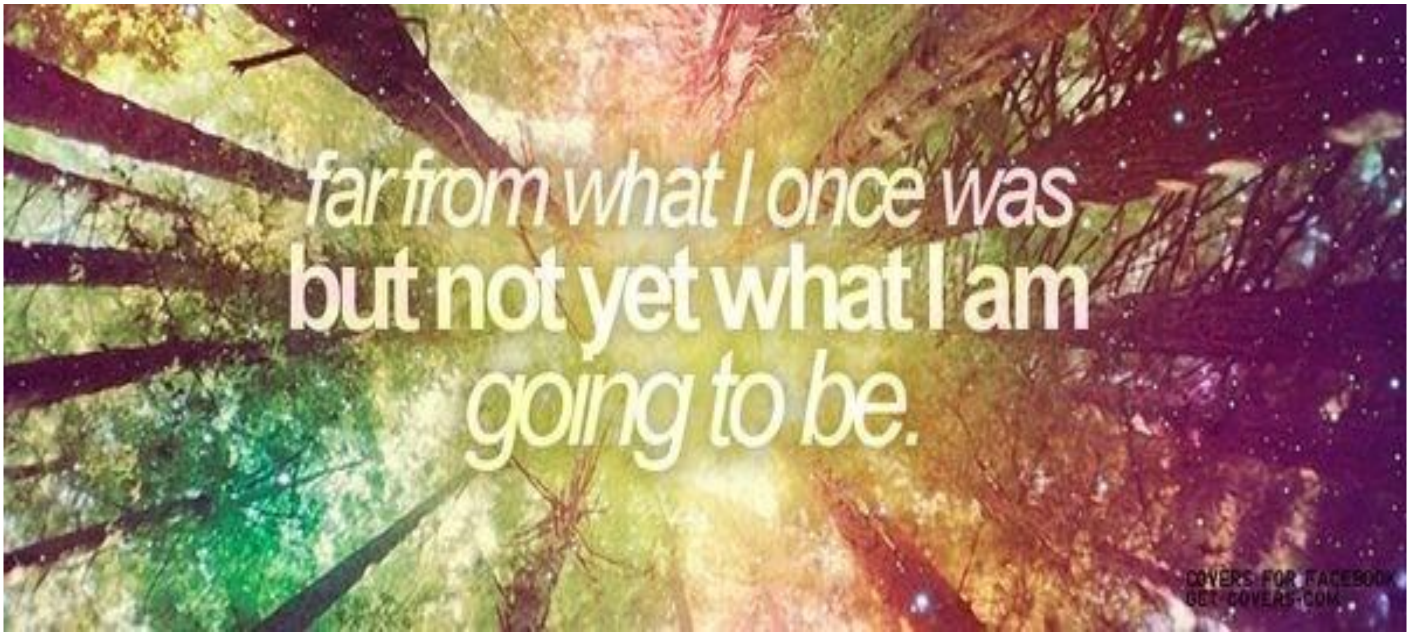
“Bad luck, sometimes saves you from worst luck”
– Winston Churchill



Don’t Forget - SPOKANE OSG MEETING – Tuesday, April 4th

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 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/

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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 Support Group, ID (# 402):

- Meetings are held from 6:30—8:30 p.m. on the 3rd Thursday of the month (January-November);
- Kootenai Health & Medical Center, 2003 Kootenai Health Way, Coeur d'Alene, ID. Classroom #2, near the cafeteria.
- Contacts: Shari Gabourie RN, BSN, CWON at (208) 625-6627 or Sherron West at 208-719-0776 for more information.

Lewis-Clark United Ostomy Association, Lewiston, ID (# 134):

- Meetings are held bimonthly at 12:30 p.m. on the 2nd Monday in odd months;
- St. Joseph Regional Medical Center, 415 6th Street., Lewiston, ID; Conference room on 2nd floor by cafeteria, generally Conference Rm. B.
- Contacts: Janet Scheelke, President at 509-305-1723; or Samantha Musser, RN-CWOCN-CFCN, Judy Reid, RN, MSN, CWON, CFCN, Jolene Tucker RN-WOC & Crystal Dewey at (208) 799-5294.

Spokane Ostomy Support Group, WA (# 349):

- 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; in the Mother Joseph Room or Leahy Room, both next to the cafeteria on L-3.
- Contacts: Susie Leonard Weller at 509-499-1423 or Carol Nelson at (Visitation Program) at 509-443-1242.

Mid-Columbia (Richland) Ostomy Support Group, (TriCities), WA (# 278):

- Meetings are held periodically from 12 noon to 1:30 p.m.
- Kadlec Healthplex,1268 Lee Blvd, Richland WA; room varies.
- Contacts: Wayne Pelly (Visitation Chairperson) at 509-943-3223, or Lisa Bartholomew, RN, BSN, CWOCN at 509- 946-4611 Ext 5562.

Confluence Health (Wenatchee) Ostomy Support Group, WA (# 398):

- Meetings are held quarterly at 2:00 to 4:00 p.m. (see contacts for meeting schedules and agendas.
- Confluence Health Central Washington Hospital 1201 S. Miller St., Wenatchee, WA, Conference rooms F & G.
- Contacts: Tyree Fender, RN, BSN, CWOCN at 509-665-6156, or Dr. Katharine Jackson at 509-663-8711, ext. 5430.

Yakima Ostomy Support Group, WA:

- Meetings are held bimonthly at 10:00 to 11:00 a.m., generally on the third Tuesday of January, March, May, September, & November (check with the inpatient wound care department for details);
- Virginia Mason Memorial, 2811 Tieton Drive, Yakima, WA, usually in basement – Classroom C;
- Contacts: Virginia Mason Memorial 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)*.