Vol. 4, Issue 1, September /October 2019



# The Advocate

## Greater Eastside Ostomy Support Group

IN THIS ISSUE	PAGE
Fall/Winter Schedule	1
Fall Annual Registration Ostomy Awareness Day	2
August Summer Social	3
Ostomy Supply Closet Personal Stories Request	4
Run for Resilience Stoma Birthdays	5
"Anything but that" was the first thought I had when I learned about ostomy surgery	6
This ostomate's book reminds us all that 'Courage Takes Guts'	7
UOAA Emergency Supply Resource Contacts	8
Find Solutions to Problems That Can Occur With an Ostomy	9
Contact Info	10
GEOSG Registration Form	11



#### Fall/Winter Schedule Upcoming Meetings

Date	Time	Topic/Speaker	Room
9/4/19	Wed 6:30—8:00 pm	Welcome back; Fall Registration Drive; Discussion Topic: Ask the Ostomy Nurse	Tan 138
10/2/19	Wed 6:30 – 8:00 pm	Fall Registration Drive; Board Elec- tions; Discussion Topic: Break-out session into ostomy types	Tan 138
11/6/19	Wed 6:30-8:00 pm	Speaker: TBD	Tan 119
12/4/19	Wed 5:30-8:00 pm	December Holiday Social	Tan 101
1/1/20		Holiday / No Meeting	
2/5/20	Wed 6:30-8:00 pm	Speaker: TBD	TBD

# **Happy Fall**



#### **Annual Fall GEOSG Registration**

While formal membership is definitely not required to attend the Greater Eastside Ostomy Support Group, we encourage and are very grateful to everyone who registers each year and donates funds to the group. These funds go towards the group's expenses for the Ostomy Supply Closet (see page 4), invited speakers, UOAA Affiliated Support Group membership, brochures and website fees.

There is a registration form at the back of this newsletter. Please fill out the form and bring to the next meeting that you attend or mail your form to the address provided on the form. Registration forms for the 2019/2020 (September – June) year will continue to be available at the remaining meetings. Forms are also available on the website at www.geosg.org.



Join with UOAA and the entire ostomy community to spread the facts about life-saving ostomy surgery and stop stigmas once and for all. Learn about the many ways you can make an impact on this day

at:

https://www.ostomy.org/ostomy-awareness-day/



## **August Summer Social**

A great time was had by all at our annual August Summer Social. We had about 30 attendees and a great time was had by all. There were stimulating conversations, and of course, there was a ton of great food.

Thank you to Tom & Terry Marinkovich (Laurie's sister & brother-in-law) for opening their home and being so welcoming to our group.



#ostomysupplyclosetcares

# The Ostomy Supply Cl<del>y</del>set

Maintained by local ostomy support groups associated with

The Ostomy Supply Closet provides supplies free of charge to anyone with an ostomy that has a need due to lack of insurance coverage, financial hardship or is in need of emergency supplies. The program is totally dependent on donations for the supplies and the cost of the storage. If you have extra, unneeded supplies, please consider donating them to the Ostomy Supply Closet. Those who benefit from this program greatly appreciate the much needed help.

The supply closet is located at a Public Storage in Kirkland. If you would like to donate, have a need, or know someone who is in need, please email Laura Vadman to arrange a time to meet and pick up needed supplies. (lovadman@hotmail.com)

Tax deductible cash donations to GEOSG for the support of the supply closet are accepted and are greatly appreciated. 501(c)(3)



Would you be willing to share your story?

What led up to your ostomy surgery? How have you handled the difficulties that are inevitable when recovering from your surgery? Do you have any special "tricks of the trade"? Do you have any funny stories to tell?

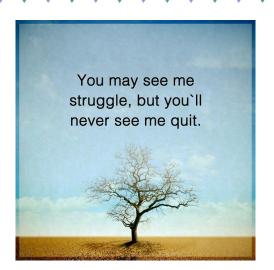
Have you travelled with your ostomy? Do you have any pictures to share with the group?

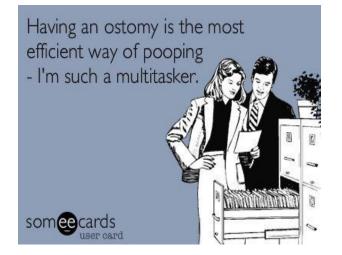
Would you rather write up your story anony-mously?

We're looking to inspire, comfort, encourage and possibly even entertain those who have new ostomies and those who may be facing ostomy surgery.

One story for every newsletter would be fantastic. If you are willing to share, please submit your written story to Laurie at lauriecmrn@aol.com.

This is a wonderful opportunity to not only feel empowered by your own journey, but to also assist those who are just starting down the path.





Life is a gift. Never forget to enjoy and bask in every moment you are in. - Unknown -

Greater Eastside Ostomy Support Group



#### 5th Annual Vancouver, WA Run for Resilience Ostomy 5K

#### October 5 @ 9:00 am - 12:00 pm - \$15.00

Website: https://runsignup.com/WAostomy5k

Ready, set, go! It's time to get your walking or running shoes on and plan to participate in UOAA's 5th Annual Vancouver, WA (formerly Portland, OR) Run for Resilience Ostomy 5K on Saturday, October 5, 2019.

NEW this year, the Fun Run/Walk will take place at Marine Park, located at SE Marine Park Way & Columbia Way, Vancouver, WA. This 58.3-acre community park is connected to Esther Short and Wintler parks by the Columbia River Renaissance Trail.

This Run/Walk is held annually 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. We encourage you to invite your family, friends, co-workers, caregivers and others to join you at this special event to walk, run or just enjoy the family-friendly festivities.

All proceeds benefit the United Ostomy Associations of America, Inc. (UOAA), a 501(c)(3) organization. Donations are tax deductible.





#### **GEOSG MEMBER STOMA BIRTH DATES**

September	Ostomy	Years
Ro MonCrieff	Ileostomy	70

October	Ostomy	Years
Ted Jamieson	Colostomy	4
Tom Davis	Urostomy	5

## "Anything but that" was the first thought I had when I learned about ostomy surgery

Adjusting to life as an ostomate takes time. By <u>Doug Dallmann</u>



When I was told that a stage III rectal cancer diagnosis would result in wearing an ostomy bag, I

was revolted. Having a hole cut into my abdomen where my colon was exposed and waste pouring out simply disgusted me. I did everything I could leading up to surgery to have a complete response to chemotherapy and radiation treatment.

Alas, it was the day of my surgery. I was able to make out a nurse saying, "looks like he has an ostomy." I was crushed. Over the next few months, I got used to it but still hated it. I hated how it looked, the noises it made, and dealing with it throughout the day. In the beginning, being an ostomate was filled with uncertainty, anxiety, and depression. I made a physical recovery within a few months and reached my "comeback" goal with a 100-mile century bike ride. That really picked up my spirits. I've always been an athletic guy and I told myself that I'd be fine, as long

as I was able to be physically active and do all the things I enjoyed before surgery.

Adjusting to other aspects of my life would take a few more years. For example, I had to navigate dating with an ostomy and figure out when to tell my date about it. I also learned how to do <u>colostomy</u> <u>irrigation</u> so that I could spend an entire day without having any output.

It was regaining my selfconfidence that took the longest, but being featured as a model for <u>The Colon Club</u> in their 2013 Calendar helped me believe in myself tremendously. The icing on the cake of confidence came after I competed in bodybuilding. I stood on the stage in front of people judging my physical appearance while wearing nothing but a spray tan, board shorts, and a colostomy bag — I knew this is where I wanted to be.

Life with an ostomy has its challenges, no doubt, but when problems crop up you just need to be prepared. I've learned the hard way to always carry along ostomy

supplies. Now I keep extras at work, in my car, in my bookbag, and in my back pocket. But if you're not prepared, just roll with it. When there's no proper bathroom nearby, I make do with what's available. I've irrigated my colostomy in a bathroom on a moving train, in a portable restroom, and even in the outdoors while backpacking. If accidents happen, it's going to be embarrassing if not downright humiliating, but don't beat yourself up. Those around will usually be very understanding and help you out.

There's no reason why you can't try everything. If you have an ostomy, go out and live the life you were going to live anyways. I've always wanted to compete in bodybuilding, hike the Pacific Crest Trail, and travel internationally. I've done all these things since my surgery because <u>other</u> <u>ostomates inspired me</u> that it can be done.

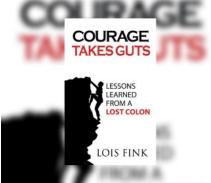
This post appeared on <u>Colon Cancer Coalition</u> and is reprinted with permission.

So far you've survived 100% of your worst days. You're doing great. "NEVER NEVER NEVER Give Up."



# This ostomate's book reminds us all that 'Courage Takes Guts'

You'll laugh, you might even cry, but most of all you will come away feeling inspired By Verena Hutter



"Have you ever thought of writing a book?" That was something Lois Fink heard from friends and colleagues countless times, and so, in 2016 she wholeheartedly made the decision to write "<u>Courage Takes Guts,</u> <u>Lessons Learned From A Lost Colon</u>". One and a half years later, the book was finished and self-published in April 2017.

"Memories I thought had been dealt with, surprised me. Tears streamed down my face as I relived what I was writing. There were times I was exhausted, but overall, I experienced a sense of closure." – Lois Fink

Lois was diagnosed with Crohn's disease in 1966, had life-saving ostomy surgery in 1986, and made a career of advocacy as a motivational speaker. At age 14, she knew something was wrong. She was underweight, not menstruating, suffering from leg cramps, fatigue, and in constant pain. Initially misdiagnosed as growing pains, her ongoing symptoms were dismissed as psychological issues. "I was running the risk of being admitted to a mental hospital," she says in the book. That blatant rejection is a stark reminder of how far gastroenterology has come and sheds light on why the instincts of young patients should be taken seriously. "I knew I was very sick," was her reaction after being diagnosed with inflammatory bowel disease (IBD).

However, she never pitied herself and continued to live her life. Lois went on to attend college, moved to Denver, and later to Seattle. After enervating issues from Crohn's, she undergoes several more surgeries including a permanent ileostomy. Lois describes the anxieties being a new ostomate but when she meets someone else who also has an ostomy, it eases her fears.

"I experienced freedom for the first time in twenty years: freedom from bowel incontinence, freedom to walk in the park, watch a movie, or enjoy a meal without running to the bathroom; freedom to really listen to someone while they spoke instead of worrying if my body would be-tray or embarrass me."

Her dry wit underscores an important message in the book about stigmas surrounding bowel disease and, in particular, ostomy surgery. While Lois admits to setbacks – such as pouch leaks or men not dating her after she disclosed her ostomy – her story is one of strength, optimism and in the end, hope. Lois writes, "In the middle of a crisis it's difficult to ask what benefits this might ultimately bring us, or what gifts we might receive if we're willing to see the situation in a different light. When we change how we view our circumstances, our life changes. We can learn to be grateful."



The book also features perspectives from <u>Joanna Burgess</u>, an ostomate and nurse, who shares her personal and professional journey. The final section contains a glossary of important terms and a thorough list of resources ranging from advocacy groups and online communities, to ostomy manufacturers and support for children and teens with ostomies.

From start to end, self-publishing has been an eye-opening and empowering experience for Lois but adds, "I'm glad I did, but I'm a one-book woman!"

## **UOAA Emergency Supply Resources**

UOAA recognizes that you may have a need for emergency supplies. Below are resources that may be of assistance to you on a temporary basis. UOAA does not have ostomy supplies in the national office.

#### **Manufacturers Assistance Programs**

Please **call directly** to ask for information and to apply for these programs.

ConvaTec 800-422-8811

Hollister 800-323-4060

Coloplast – Coloplast Patient Assistance (C.P.A.): 877-781-2656

## **Alternative Local Resources**

Contact the following types of agencies in your area, and ask if they maintain a "Donation Closet".

- Local hospitals
- Local Visiting Nurse associations
- Local clinics
- Local Goodwill Industries

Call your state's 2-1-1 number. Just dial 211 as you would 911.

UOAA has Affiliated Support Groups who sometimes operate Donation or Supply Closets.

Kindred Box is a Facebook Group for Ostomy Supplies

## Supplies Available with S + H

#### Osto Group: 877-678-6690

Offers supplies for the cost of shipping and handling. They have a small all-volunteer staff, but if you call and leave a message, they will respond. Please be patient in awaiting a response.

**Ostomy 211:** <u>ostomysupplies.ostomy211.org</u> Emergency supply pantry. Donation requested to help cover expenses.

## **Lower Cost Supply Options**

There are several distributors that do not accept insurance, therefore, their supplies may be available at a lower price.

Best Buy Ostomy Supplies: 866-940-4555 Mercy Surgical Dressing Group: 888-637-2912 Ostomy4less: 877-678-6694; contact Patti or Tom at patti@ostomymcp.com Parthenon Ostomy Supplies: 800-453-8898 Stomabags: 855-828-1444

## Find Solutions to Problems That Can Occur With an Ostomy

A Coloplast article from https://www.coloplast.us/

Many people with an ostomy find that once their stoma has settled and they are in a normal routine, they are able to live their life with few ostomy related issues. However, as you are adjusting to life with a stoma, you may experience some problems that are quite common. We have put together a list of some common ostomy related problems and solutions so you can be well prepared if and when they occur.

# Many ostomates continue to live with stoma issues and problems unaware that there are solutions available to them.

Learning how to care for your stoma and understanding these common problems will help you to find normalcy and routine after your surgery. Access to this information will help you to take charge of your life and increase your confidence.

Before we get into the common problems and solutions, it might be helpful to mention proper cleaning and application. With proper care of your stoma and the skin around your stoma you may reduce the risk of the below problems. Proper care begins with proper application. Make sure your barrier hole fits tightly around your stoma, and that the skin is clean and dry for application. When removing your barrier, it is important to lift it gently off of your skin while using your other hand to press down on your skin. Ripping the adhesive off quickly can cause redness and irritation that can lead to other problems. To clean your stoma and the area around it, use a soft cloth or towel and warm water. Be gentle when cleaning, as aggressive rubbing or wiping can irritate the skin. It is not necessary to use soap, as soaps can leave residue and irritate the skin. When changing your pouching system, it can be helpful to use a small hand-held mirror to see all around it. If there is leakage, use the mirror to check all areas of your barrier and stoma for gaps and creases. Once you've identified the problem area, it will be easier to address.

#### Leakage

Two of the main factors of leakage problems are: how you prepare your skin before you apply your barrier, and your barrier size. You should make sure to clean and dry your skin completely before applying a new pouching system. If you are having trouble getting the area dry, an absorbing powder might be a good solution for you. If your pouch gets too heavy and tends to pull away from your skin, or if your barrier does not fit correctly, a protective seal between your stoma and the barrier can prevent leakage and seal the pouching system.

#### **Skin Problems**

The skin that surrounds your stoma is called peristomal skin-—it should be smooth and healthy and look like the rest of your skin. If it is red or irritated, you should address the problem immediately. If you have problems with adhesive residue or are unable to get the area completely clean before application, you may want to try to use an adhesive remover.

#### Odor

New sound and smells coming from your pouching system can be embarrassing and induce anxiety. Many new pouching systems have filters to neutralize the odors caused by gasses in your pouch. What you eat can have an effect on gasses you produce. It is recommended to avoid carbonated beverages and limit high-fiber foods. If the filter in your pouch gets blocked, you may experience ballooning. Ballooning happens when air from your stoma cannot escape the bag and it fills up like a balloon. Depending on the type of system you are using, you may want to release air from it throughout the day. If the odor is strong when you are changing your pouch, you may want to try a lubricating deodorant which can help mask, the smells during a pouch change. Simply place 6-10 drops into the pouch when you change and empty it and spread it around inside the pouch by rubbing the inner sides together, avoiding the filter. This helps the output to make its way more easily to the bottom of the pouch.

Should you need more assistance dealing with a problem you are having with your ostomy, consult your healthcare professional. For more assistance and personalized support, check out <u>Coloplast® Care</u>, which is an ongoing comprehensive support program that gives people with an ostomy support throughout their life.

### **Contacts**

GEOSG Board Contacts	E-mail
Nancy Upton, Ostomate Board President	nancyupton8@gmail.com
Quyen Stevenson, ARNP, CWOCN Board Vice-President	nursequyen@gmail.com
Laura Vadman, RN, CWON, Board Treasurer	lovadman@hotmail.com
Laurie Cameron, Ostomate, Board Secretary, Registrar, Newsletter Editor, Webmaster	lauriecmrn@aol.com





Manufacturers	Phone	Website
Coloplast	888-726-7872	www.us.coloplast.com
ConvaTec	800-422-8811	www.convatec.com
CyMed	800-582-0707	www.cymed- ostomy.com
B. Braun Medical	800-227-2862	www.bbraunusa.com
Hollister	800-323-4060	www.hollister.com
Marlen	800-321-0591	www.marlenmfg.com
Nu Hope	800-899-5017	www.nu-hope.com
Organizations	Phone	Website
United Ostomy Associations of America	800-826-0826	www.ostomy.org
American Cancer Society	800-227-2345	www.cancer.org
Crohn's & Colitis Foundation	800-343-3637	www.ccfa.org
Friends of Ostomates Worldwide	N/A	www.fowusa.org



Like us on Facebook.

www.facebook.com/ GreaterEastsideOstomySupportGroup/



We're on the web! www.geosg.org

#### Greater Eastside Ostomy Support Group Annual Membership Form 2019-2020

GEOSG Membership is open to anyone interested in learning about ostomies, sharing and learning on how to care for yourself or a loved one after surgery and what to expect before surgery. Be sure to visit our website for more information: www.geosg.org

Membership (Individual/Family)	New N	Iember (Please mar	k if this is the first time you have registered)	
Ostomate Name:	Spouse/Support Name:			
Address:				
	Email Address 1:			
Cell Phone:				
Ostomy Information				
Type of Ostomy: 🔲 Ileostomy	Colostomy	Urostomy	Other	
Stoma Surgery Date:				
Social Media				
<i>I, hereby, grant permission to Greater</i>	· Eastside Ostomy Su	pport Group to use m	y photo on the group's social media.	
		<b>Do not us</b>	e my photo.	
Signature				
There is no charge for membership, for the Ostomy Supply Closet, spea GEOSG asks that you make a tax a	ikers, UOAA AS deductible (501(d	G dues, brochur	es and the website. lieu of membership dues.	
Donation			5	
Make checks payable to: GEOSG				
A receipt for donations will be issued	l upon request.			
Return completed form to the next m	eeting or send to	:		
Laurie Cameron	Fo	r any questions of	r to receive a receipt:	
GEOSG Registrar	En	ail: lauriecmrn@	Qaol.com	
728 218th Pl. NE				
Sammamish, WA 98074				
GEOSG members often participate in ac the individual. GEOSG is neither respon	ctivities together, b sible for, nor does	ut that participatio it exercise any con	on is the choice and responsibility of trol over, these activities.	

For treasurer's use only:				
Paid Amount \$ ca	ash ch	heck	ck #	Date: