



WEB SITE: www.ostomysolano.org

SOLANO OSTOMY NEWS

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2021

DATE: August 5th and 19th **VIDEO METINGS******

**HOSTS: August 5th at 7:00 pm – Hosts: Peggy Terry & Dan & May Lou Santillo
Program – Mary Lou Santillo, CWOCN, Vacaville Kaiser - Joining our
Meeting for Introductions**

**August 19th at 7:00 pm – Hosts: Peggy Terry & Dan
Program – Theresa Johnson, Dir. of Customer Relations, Stomagienics**

REFRESHMENTS: BYOB (Bring Your Own Beverage)

WHERE: In Your Living Room, Kitchen, Dining Room – You Pick It

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JUST A FEW COMMENTS

Wow its mid-July already. I think I am tired of hot summer days already. Interestingly, last Saturday it was 108 degrees in Vacaville, and we were in San Francisco, and it was only 65-70 degrees and cold and windy. Crazy, but I guess that is not unusual for San Francisco?

Last month, we had a couple great meetings. On **June 3rd**, we had **Donna Ruryk** from **Trio Ostomy Care** who discussed Trio Silicone Ostomy Accessories. Interesting products. I have started using their skin barrier product that actually protects the skin and **improves** wear time, as opposed to Cavilon which actually **decreases** wear time. On **June, 17th** we had two **TSA Representatives** join our meeting and they discussed changes in future airport security, especially as it relates to **ostomates**.

Upcoming on August 5th, we will have **Mary Lou Santillo** join our video meeting. **Mary Lou** is the new **CWOVN** at the Kaiser in **Vacaville** and she will be participating in our group both at **Video** meetings and future **In-Person** meetings. We are looking forward to taking advantage of her expertise and guidance. I will have more on her stats in the near future. Peggy will also be there, and we will have our usual roundtable as well.

Upcoming on August 19th, **Theresa Johnson**, Director of Customer Relations for **Stomagienics** will be joining our meeting to discuss the Somagienics product line. Stomagienics makes a product that enables you to take your time, making pouch changes without the mess involved, especially for Ileostomies and Urostomies. Here is the link to their interesting website: www.stomagienics.com.

Speaking of meetings, I am working with Peggy and Mary Lou on **restarting in-person** physical meetings. Maybe by the 3rd week of September or it may end up in October. Either way, it will require certain things to happen. **1.** Can we get our old meeting rooms in Vallejo and Vacaville. **2.** When will Kaiser allow gatherings again. **3.** Will masks and distancing be required. **4.** Will all members be required to have **full vaccination**. **5.** Will we meet on Thursday or Wednesday as we used to meet. **6.** Do we want to continue having at least one Video meeting each month as well. **7.** Other things I have not considered. **We will keep you posted on this important topic.**

Be careful out there!!

Upcoming Meetings – Add to Your Calendars – Details to Follow

August 5th – Hosts: Dan and Peggy + Mary Lou Santillo, CWOCN's
Introduction - Mary Lou Santillo, New WOCN – Vacaville Kaiser

August 19th – Hosts: Dan and Peggy, CWOCN
Guest – Theresa Johnson, Director of Customer Relations, Stomagienics

September 2nd – Hosts: Dan and Mary Lou Santillo, CWOCN
Tentative: Roundtable Discussion and Support + Potential Guest



Ask Nurse Coulter

Barrier Ring Mess

I tried a new barrier ring and the same night had a "blow out" which I blame on the pouch. When I went to remove the pouch and barrier ring, there was adhesive stuck all around my stoma from the ring. It took a lot of adhesive remover to remove and made my skin sensitive. Is this normal? Seems like something was wrong.
N.P.

Dear N.P.,

I'm sorry to hear about your blow out and the issue you had removing the ring from your skin. When it comes to barrier rings "normal" varies by brand. Each pouch manufacturer offers their own ring brand and some offer more than one type. Each brand is made with a proprietary formula, the specifics of which are kept under lock and key. Some ingredients include hydrocolloids like pectin, which will absorb moisture, polymers to provide elasticity, and tackifiers, which make the ring sticky. Because the ring recipes vary, the performance of the rings vary also. Some hold their shape better than others. Some swell more than others. Some are easier to stretch, and some adhere more or less strongly than others. Some people may find that their skin is sensitive to ingredients in one brand of ring, but not another.

All of this is to say that what you encounter may not be unusual for the new-to-you ring that you tried. I'd encourage you to try some other brands to see which is most comfortable and which works best for your stoma and pouch. Most companies will provide samples. Look at their websites for a "request a sample" link. If you paid for a box of the rings and you are not satisfied with them, either your supplier or the manufacturer should provide a replacement. When contacting the manufacturer, let them know the issue that you had and provide the lot number, which is found on the box. They will be glad to receive your feedback and may use it in future product development or to determine potential production issues.

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THERE ARE APPROXIMATELY 725,000-1 MILLION PEOPLE IN THE U.S. WHO HAVE AN OSTOMY.

People of all ages have life-saving ostomy surgery for a wide variety of reasons and most go on to live active and healthy lives. You have very likely already met someone with an ostomy but never knew it. **UOAA** can help you find the answers you need as you begin your "new normal" life and can connect you to resources to help ease the physical and emotional changes ahead. After recovery and finding the right pouching system to fit your body, you should expect to resume an active life in work, play, and with family and friends.



Remember your ostomy can bring order out of a disorder that could have disrupted or ended your life.

Protecting My Stoma

Via New Directions, R. W o m TX

Stomas are hardy but some commonsense rules apply. Stomas should be protected from direct physical blows. This can occur from too tight clothing, contact with rigid objects - belt buckles, pushing against something with them- like a snow shovel, etc. People with ostomies engaged in contact sports should protect their stomas by wearing an ostomy system without any rigid parts and if necessary, by wearing a stomal cover made to protect it from blows and hits. [Dr. Katherine Jeter](#), writing about children with stomas, in [These Special Children](#) states: "**Stomas may be slept on, rolled on, and even sat upon by another child for a few minutes without undue concern.**"

What is involved in a stoma inspection?

At each pouch change, check your stoma for color, shape and function. Watch for any stoma concerns, such as swelling, retraction, stenosis, or prolapse. If you have urostomy, you should be on the alert for crystal formation or alkaline encrustation-gritty white deposits coating the stoma. Any stomal complication should be reported to your ostomy nurse.

Why will the stoma bleed sometimes?

Because the mucous membrane out of which the stoma is formed is so highly vascular, some bleeding may occur with rubbing of the stoma. This bleeding should stop quickly. Prolonged bleeding or an increased amount of bleeding could indicate another problem, which would be prudent to report to your ostomy nurse.

Can a stoma be cut?

Cuts or lacerations of the stoma can occur, and some can be quite serious. Because a stoma has no sensory nerves - and therefore no feeling, although a blocked stoma demonstrates that there are still quite a few nerves there of a different type - it can be cut without you actually feeling it. Causes of stoma lacerations include shifting of the barrier, too small an opening for the stoma, incorrect pouch application, etc. Consult your ostomy nurse for diagnosis and treatment in any case of stomal laceration.

Ask Nurse Anita

Urostomy Odor

My bladder was removed in 2015 due to cancer and an ileal conduit, or urostomy, was created. I am happy with my two-piece system. I'm told that the urostomy harbors bacteria like a healthy small intestine and that's the reason for a strong odor. Is there something I can take orally or put in my pouch to suppress the odor?

B.H.

Dear BH,

Odors are a common concern for people with urostomies. Urine has a natural odor that smells like ammonia. When people with urostomies complain of strong urine odors, I **immediately think urinary tract infection (UTI)** but there are several other reasons for malodorous urine. First let us review signs and symptoms of a UTI: strong odor to urine (caused by bacteria), accompanied by any of the following: cloudy urine, flank pain, abdominal pain, fever, chills, confusion, and malaise.



Urine infections in people with urostomies can often be overlooked due to vague symptoms compared to individuals without diversions – who complain of frequency, difficulty emptying their bladder and burning with urination. Remember to remind your practitioner that **urine cultures need to be done by inserting a sterile catheter into the stoma, not taken from the pouch**. The small intestine, or ileum, used for the “conduit” does indeed contain bacteria which puts urostomates at a higher risk for UTI’s and pyelonephritis (kidney infection). Up to 80% of patients with urostomies will have asymptomatic bacteriuria which does not require antibiotics. And up to 44% of patients will develop a UTI after radical cystectomy surgery. The microbiota of the small intestines is typically aerobic which does not produce gas and foul odors as compared to the anaerobic bacteria of the colon. The human microbiome is a fascinating new world that is just beginning to be understood. Urine can also smell “strong” when you are dehydrated. Dehydration causes the urine to be more concentrated and will appear darker yellow or even orange in color and have a strong odor. When you are well hydrated, your urine will appear a light yellow or straw color. Are you drinking enough water and fluids throughout the day? Adequate hydration is also important to prevent infections. Recommended fluid intake is 1

SOME BASIC OSTOMY HINTS

- **Don't** feel that having an ostomy makes you less of a person or some freak of nature. There are lots of us and most of us are glad to be alive.
- **Build** a support system of people to answer questions when you have a problem. Consider our ostomy nurses and your officers who are listed on this website.
- **Don't** play the dangerous game of making your appliance fail by putting off a change. There aren't any prizes given for the longest wear time except accidents.
- **Don't** wait until you see the bottom of your supply box before ordering more. Always expect delays in shipping when calculating delivery times – although most suppliers can deliver ostomy supplies to you in a day or two.
- **Zip-lock** sandwich bags are useful and odor-proof for disposal of used ostomy pouches.
- **Don't** get hung up on odors. There are some great sprays, drops and some internal deodorants. Remember, everybody creates some odor in the bathroom. Don't feel you are an exception.
- **If** you have a urostomy, you might be concerned about urine odor. Certain foods can cause a stronger urine odor, but you can minimize that by drinking water or cranberry juice.
- **Carry** an extra replacement pouching system in case you spring a leak while away from home. Rotate the ostomy products in your emergency kit so they do not become outdated.
- **Re-measure** your stoma to ensure the correct size of pouch and skin opening. The stoma will shrink in the first few months after surgery.
- **Read** and learn all you can about ostomies. You will not only serve yourself, but you never know when you may find an opportunity to educate someone about the life-saving surgery that has extended so many of our lives.
- **Learn** to be matter of fact about your ostomy surgery and never embarrassed. Few folks get out of this life without some medical problems and unpleasant situations with which to cope. You may be amazed at how people will admire your adaptability and courage.



In the beginning after surgery, almost everyone experiences some depression. If you fit into this category, you are certainly not alone. But it need not be a lasting condition. If the depression seems to linger, don't be afraid or ashamed to seek professional help. There is help out there!

The bottom line is...we are alive! If we lived just a few years ago, or in another country, we might not be. Medicine and techniques today have given us an opportunity to experience this second chance. It is certainly an opportunity worth accepting and exploring. The most important part of you as a human being has not changed.

OSTOMY ASSOCIATION OF GREATER CHICAGO

Stigmatized

Educating the public that ostomies are life savers, not death sentences.

By Kimberly Kidd

Recently, I came across situation that broke my heart and urged me to step up and do everything I can to make a change. First, I want to tell my story. I was newly married at 28 with an eight-year-old and three-year-old when an 18cm tumor was found where the colon meets the rectum. I was given a 30% chance to live and my stoma was born. After radiation and chemotherapy, I endured three more surgeries. I beat the odds and was clean for 23 years. Then again cancer was found. I had a resection that went well, although malignant cells were "spilled" into my abdomen and two years later a tumor was found behind my stoma. Then it was decided to take out the rest my colon to prevent a recurrence. I am a carrier of lynch syndrome, the genetic disposition to colon cancer.

Over the years, I have come across people, even friends, who did not know about my stoma and they spoke very negatively and degrading against others who had stomas. This shame has curbed some of my life, but I have worked 10 years as a lunch lady, six years as a waitress and in a shop for five and I have still enjoyed it well.

A friend just told me about her dad. He was told he would need a stoma due to rectal cancer. He is only 58. Because of this stigma of an ostomy, **he said he would rather die**. When I hear something like this, I think, if someone had cancer in their leg, they probably wouldn't think twice about amputation. But a stoma is somehow a death sentence. It's time for a change and education. I want to make a stand for my generation who has been living with the "old school" ideas about ostomies. I want to let them know stomas are as clean as you keep yourself. They don't have to smell and are easily controlled. Ostomates can be and do anything they want. It is all about adapting to a different way of life, not a worse way of life. I want to be truthful. There are definitely times I am bummed about being different, usually when I am having leaking issues, but they get ironed out. Don't we all have bad days? So, fellow ostomates, let us spread the word. I feel that more change can be made. Feel free to contact me at garde65@yahoo.com

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LEARN HOW TO SPOT PERISTOMAL SKIN IRRITATION AND DAMAGE.

After your ostomy surgery, your healthcare team likely taught you how to care for your peristomal skin and what it should look like when it is healthy. Ideally, it should be intact without irritation, rash, or redness. The skin around your stoma should look just like the skin on the other side of your abdomen, or anywhere else on your body, free of redness, irritation, or damage. Healthy skin should be the rule, not the exception.



However, if your peristomal skin is irritated or damaged, there may be some signs of a peristomal skin complication (PSC), such as:

1. Discomfort, itching, soreness, or even pain around the stoma
2. Recurrent leakage under your pouching system or skin barrier
3. Excessive bleeding of your stoma – it's normal for your stoma to slightly bleed after you wash it, but the bleeding should resolve quickly
4. A bulge in the skin around your stoma
5. Skin color changes from normal pink or red to pale, bluish purple, or black
6. A rash around the stoma that is red, or red with bumps – this may be due to a skin infection or sensitivity, or even leakage
7. Wart-like, pimple-like or blister-like bumps under the skin barrier – this type of irritation can happen any time, even if you've used the same product for months or years
8. Any type of wound or scratch on the peristomal skin

PERISTOMAL SKIN COMPLICATIONS — POTENTIAL CAUSES AND WHAT TO DO

Irritated and damaged peristomal skin can occur for a variety of reasons. It can be caused by anything from a poor-fitting pouching system, to frequent skin barrier changes, to an allergic reaction to anything that contacts the skin, such as soaps or products used to prepare the peristomal skin. Some studies report up to 75 percent of people with an ostomy experience a PSC.* Although it is a common issue, it should not be ignored.

If you experience any signs of a PSC, contact your stoma care nurse. You should work with your healthcare team to determine the exact cause and the appropriate solution.

For more information on maintaining healthy skin and other topics, [click here to visit the Hollister Ostomy Learning Center](#).

* Rapp CG, L Richbourg, JM Thorne. Difficulties Experienced by the Ostomate After Hospital Discharge. JWOCN. 2007;34(1):70-79.

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