



WEB SITE: [www.ostomysolano.org](http://www.ostomysolano.org)

# SOLANO OSTOMY NEWS

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**2020**

**DATE: NO MEETING FOR THE MONTH OF JULY**  
**NEXT MEETING – AUGUST 19<sup>TH</sup> (DEPENDING ON COVID-19 STATUS)**

**SPEAKER: DAN AND PEGGY**

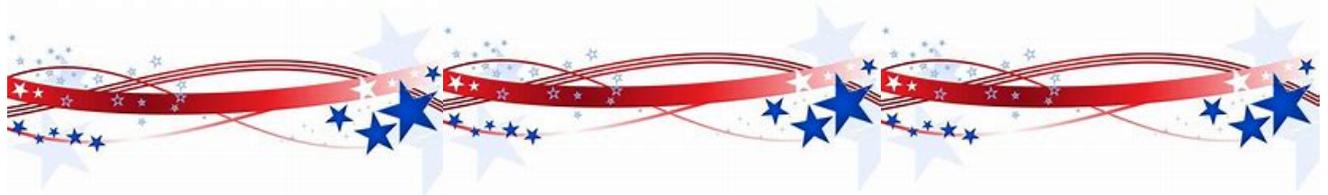
**PROGRAM: ROUNDTABLE DISCUSSION - Q & A - WITH PEGGY TERRY, CWOCN**

**REFRESHMENTS: DAN BRUCE**

**WHERE: KAISER VALLEJO, 975 SERENO BLVD.**

**MEETING ROOMS A&B, FIRST FLOOR. HALLWAY PAST PHARMACY #1**

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## JUST A FEW COMMENTS FROM THE PEANUT GALLERY

**Wow** – I cannot believe it is almost July. I hope everyone is healthy and virus free! Time flies even when we are in isolation and distancing from most family and friends. With all the news regarding the Covid-19, protests and violence in the streets and the political quagmire, I am trying to avoid the news as much as possible. I am looking forward to better times, travel and socializing with family and friends. Maybe if everyone wears a mask as recommended and is careful, we can get back to normal – whatever that may be - sooner than later.

**On another note**, I will be sending out a quick survey to all members regarding the future of our group. We need to look at ways to improve active participation of members in the group, consider how to increase attendance at future meetings, and actively recruit new members. I have been tracking attendance over the last few months, and attendance at meetings is quite small, considering that we have almost 50 members, we are getting only about 3-4, sometimes 5, members attending monthly meetings and the numbers are even smaller in Vacaville. That number does not include me or family members who attend. We did have a larger group attend when Dr. Chae came to our meeting in Vallejo. Anyway, I would like to study ways to improve our group and recruit new members.

**Sorry, just one more business item.** Of the almost 50 members, **only about half**, have paid their dues for 2020. I realize that we do have a healthy balance in our accounts, but most of that money is because of a large donation. That balance is slowly going down, as we spend more than we take in each year; and if nothing else that money can help support sending a couple kids to **Youth Rally** every year. Thanks to those members who have already paid.

**One more.** Since we have not been meeting each month, we are not there to support, assist and encourage fellow members or new members. Please remember that our CWOON supporters, **Peggy Terry** in Vallejo and **Mary Ann Chico** in Vacaville are available to help members in any way they can.

Be careful out there!!

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### Upcoming Meetings – Add to Your Calendars – Details to Follow

**August 19<sup>th</sup> – Vallejo Kaiser** - Conference rooms A, B and C. Hallway past pharmacy #1  
**Tentative: Roundtable Discussion and Support**

**September 16<sup>th</sup> - Vacaville Kaiser** – 1 Quality Dr., Building B, Meeting Room H1A 1<sup>st</sup> Floor  
**To Be Determined - Tentative: Roundtable Discussion and Support**

**October 21<sup>st</sup> – Vallejo Kaiser** - Conference rooms A, B and C. Hallway past pharmacy #1  
**Tentative: Roundtable Discussion and Support**



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### Five Very Good Reasons Why It's Awesome to Have an Ileostomy

**Now I feel it's my turn to spread the good word.**

Leah's Life, Lemons & Lemonade

I was diagnosed with Crohn's disease when I was 20 and I've been living with an ileostomy since 2008. The one phrase I've heard over and over again is... **"I don't know how you do that. I could never do it."**

Occasionally, I've also heard... **"I'd rather die than have to live with an ostomy."**

The first one is understandable because it was scary for me to think about living with one. I wasn't excited about surgery and never once said, "Yeah, I totally want to do that!" The truth is, I went through with it because it saved my life. It's the hand I was dealt, and it all came down to accepting an ostomy as my reality.

But the second one? "**I'd rather die than have to live with an ostomy.**" That one blows my mind. Really? You'd rather die?? DIE??? **Actually, STOP living????** For someone who doesn't have an ostomy, this confirms one very obvious truth on why you could say something so outrageous. You obviously have NO IDEA what it's actually like to be an ostomate. At least to me it's outrageous because I live with an ileostomy and most of the time I don't even think twice about it.

**I'd like to point out just a few reasons why living with an ostomy is awesome (and sometimes downright hilarious).**

**1) I'm still alive and symptom-free.**

I'm just going to say this is the most obvious reason to me. I owe my life to ileostomy surgery, and for that, I'll always be grateful. I'm in awe.

**2) I never have to race to make it to the toilet.**

For anyone who's had "the runs" where you literally have to RUN to the bathroom. That no longer exists for me. There is literally no urgency anymore. I simply empty my ostomy bag when needed. Awesome right?

**3) When my stoma "farts" it doesn't sound like a fart.**

Have you ever accidentally farted at the most inopportune moment and wanted to just pass out from embarrassment? Well, I have. Thanks a lot, Crohn's disease. But now with an ileostomy, my stoma noises don't actually sound like a fart. Plus, nobody else will smell anything (it's in the bag 😊) and they probably won't even know what the noise was, much less who it came from. Awesome!



**4) It takes hardly any time to "go" with an ileostomy.**

How much time do you waste sitting on the toilet going #2? If you're a person with inflammatory bowel disease or other digestive disorder, then it's probably A LOT. With an ileostomy, that went away for me. I go into the bathroom, empty my bag, wash up, and I'm done. It literally takes me the same amount of time to empty, as it does to pee. That is awesome!

**5) I don't actually have to touch yucky public toilets.**

Okay, so this is probably my favorite thing about living with an ostomy. You know when you walk into a public restroom and it's DISGUSTING? And what about using a port-a-potty? GROSS! Then it occurred to me, I don't actually have to touch it. I can lean over and empty into the toilet without ever sitting on the seat. How many of you can do that? Well with an ostomy, you can. It's awesome!

I hope what I've shown you that not only is this life-saving surgery but that it can change your life for the better. YOU. CAN. DO. THIS. I promise.

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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 common sense 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.



## Wonderful Witch Hazel

**A reader rediscovers a way to soothe her sore skin**

*By Chuckie McHenry*

**I was born with my great-grandmother's red hair.** I also inherited the sensitive skin that goes along with being a redhead. I need to use gentle soaps and skin products. When I was a baby, I developed a rash from the most popular baby lotion at the time. If I wear adhesive tape for more than 24 hours, my skin breaks down like it has been burned, and it can take weeks to heal. An allergic reaction to bee stings also runs in my family. Relatively benign insect bites cause large welts and intense itching. Well, this redhead also inherited familial adenomatous polyposis, a precursor to colorectal cancer. My entire colon had to be removed. I would need to learn how to live with a permanent ileostomy. As a neonatal intensive care unit nurse, I learned good ostomy care on small babies with delicate skin. That experience helped prepare me. Good skin care around my stoma became a major focus in my life. I was careful with the products I used for cleaning and prepping my skin. I washed the area very gently. I had to find the right ostomy wafers and pouches that wouldn't cause more irritation. I tried several brands and styles. Each had some great qualities that I really liked, but each had some things that didn't work for me. I put together the best combination of products that I



could. One summer the local mosquito population was vicious! I went online to research remedies that would relieve the itching from the mosquito bites and found **hamamelis virginiana, a species of witch hazel.**

Oh yeah, good old witch hazel! I used it for all sorts of things when I was a teenager. It was a gentle astringent for my face. It was soothing for bruises and helped with itchy skin. Why did I ever stop using it? It was probably because I believed all those ads for fancy products. So, why not go back to the simple remedy that worked? I went to a pharmacy and bought a bottle. It did give me some relief from the itching caused by the mosquito bites. Then, I started to wonder...if it helps with the insect bites, it might help with the itching under my ostomy wafer. During my research on hamamelis virginiana, I discovered that it helps discourage monilial growth. Monilia is that “yeastie beastie” that likes to grow on warm, moist skin like the skin under an ostomy wafer. Of course, I am also hypersensitive to monilia.

Thus, began my “**great witch hazel experiment.**” After I cleaned my tummy with gentle soap and rinsed well (mainly using plain water), I would apply the witch hazel to the skin around my stoma and let it dry. Then, I would apply my wafer. It didn’t sting like alcohol does! Actually, it was rather soothing. It cleaned the area thoroughly and toned the skin. This helped to protect my skin and I didn’t need to use “skin prep” as often. I was not getting the itching under my wafer. So, the witch hazel had made a real difference in the skin care around my stoma. Carrying a bottle of witch hazel with me was not convenient, so when I travel, I take individually wrapped wipes. They were also handy for the “emergency ostomy kit” I carry in my purse. I had fewer problems with hard water/soft water changes that can cause decreased wafer time. I reported on my progress at my ostomy support group monthly meetings. Other people in my group decided to try it and told me that it worked well for them too. Well, my hair is now “silvering,” but I still have the sensitive skin of a redhead. So, I think “The Witch” and I will stay good friends for a long time.

**Consult a physician before starting any treatment.**

***“I didn’t need to use ‘skin prep’ as often. It was not itching under my wafer.”***

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## **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 ounce per every 2.2 pounds of body weight per day. For example, if you weigh 150 pounds  $\div$  2.2 = 68 ounces. That's roughly 4 sixteen-ounce water bottles.

**Certain foods** cause urine to be malodorous as the body breaks it down. Asparagus is a well-known food to cause smelly urine, but other vegetables such as onions, Brussels sprouts and garlic can also change urine odors. Curry, salmon, vitamins and alcohol can have a similar effect. Drinking coffee is another offender and is also a diuretic (increases urination). You are not alone in your desire to suppress the unpleasant odor of urine. Fortunately, there are several products called odor eliminators available to do just that. These products are not to be confused with fragrant deodorizers. Hollister makes **M9 Odor Eliminator Drops**® that have been around for many years. This is a blue liquid that is inserted into the pouch before application that neutralizes unpleasant odors. **Na'Scent**® claims to eliminate odors by creating an oxygen-rich environment by eliminating odor producing microbes! There are loads of odor eliminator products available in the ostomy market.



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## 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.

# 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](mailto:garde65@yahoo.com) or 989-280-3946.



The screenshot shows the Costa Medical website. At the top left is the Costa Medical logo. Below it is a photo of a person's abdomen with a stoma. The text reads "Makers of Aqua Seal & Stoma Seal" and "609-558-4254". There are navigation links: HOME, BUY NOW, ABOUT US, TESTIMONIALS, MEET THE TEAM, VIDEOS AND INSTRUCTIONS, CONTACT US, and BLOG. Two product listings are shown: Aqua Seal (6" OD 1/2" ID 10 per pack) and Stoma Seal (6" OD 1/2" ID 10 per pack). Both have "Buy Now" and "Add to Cart" buttons.

Check out this product. If you like to swim or go in the spa this looks like it would work well.

<https://www.costamedical.org/>

The poster is titled "Ostomy Misconceptions". It features a central image of a woman with a stoma, wearing a denim skirt, a black top, and colorful patterned boots. She is holding a colorful bag. Surrounding her are several misconceptions written in bold, italicized text:

- You can't date
- You can't wear what you want
- You can't exercise
- People can tell you have a bag
- You are not beautiful with your bag
- You can't swim
- You can't advocate for yourself
- You can't be intimate with your partner

At the bottom, it says: **Having a ostomy is end of your social life**

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**VISITATIONS:** OPEN.....

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**NEWSLETTER:** DAN BRUCE.....530-979-7772.

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**MEMBERSHIP:** DUES ARE \$15.00 PER YEAR, \$ 5.00 PER YEAR FOR SPOUSE. CHAPTER IS OPEN TO OSTOMATES, SPOUSES, PROFESSIONALS, SUPPLIERS AND FRIENDS. ORGANIZED UNDER THE AUSPICES OF THE AMERICAN CANCER SOCIETY.

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NAME \_\_\_\_\_ PHONE \_\_\_\_\_

OSTOMY BIRTHDAY \_\_\_\_\_ EMAIL \_\_\_\_\_

ADDRESS \_\_\_\_\_ CITY \_\_\_\_\_ ZIP \_\_\_\_\_

TYPE OF OSTOMY: COLOSTOMY \_\_\_\_\_ ILESTOMY \_\_\_\_\_ UROSTOMY \_\_\_\_\_

PROFESSIONAL OR OTHER OCCUPATION \_\_\_\_\_

IF YOU NEED A RIDE IN ORDER TO ATTEND THE MEETINGS, PLEASE CALL DAN BRUCE. HE CAN ASSIST IN ARRANGING TRANSPORTATION.

