



WEB SITE: www.ostomysolano.org

SOLANO OSTOMY NEWS

**EDITOR: DAN BRUCE
OSTOMY ASSOCIATION OF SOLANO
P.O. BOX 5142, VACAVILLE, CA 95696**

APRIL

2021

DATE: April 1st and April 15th **VIDEO METINGS**

**HOSTS: April 1st at 7:00 pm – Peggy Terry & Dan
Program - Roundtable Discussion and Q&A**

**April 15th at 7:00 pm – Peggy Terry & Dan
Special Guest - Potential Guest: Nancy Stevens, Byram Healthcare**

REFRESHMENTS: BYOB (Bring Your Own Beverage)

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

The documents contained within this newsletter are presented expressly for informational purposes only. In no way are any of the materials presented here meant to be a substitute for professional medical care or attention by a qualified practitioner, nor should they be construed as such. ALWAYS check with your doctor or CWOCN.



JUST A FEW COMMENTS

I hope this finds everyone happy, healthy and virus free. **Spring has sprung**. The trees are all leafing out, things are greening up, plants are starting to bloom, and temperatures are rising. Spring is my favorite time of year, and I am feeling more confident that the virus is diminishing, and we will be able to return to some form of normal again. Hopefully, most of you have gotten your vaccinations, and feel like I do, that a weight has been at least partially lifted off my shoulders.

At the March 4th meeting, William Lorimer with **Ostoform** joined us from Ireland at **3:00 am** in the morning to discuss their new **unique ring type** ostomy accessory. This is an interesting product that is probably most useful for an Ileostomy, but would also be useful for Urostomy's as well. To get a sample: www.ostoform.com Click on "free sample" on top menu.



At the March 18th meeting, we had Michelle Bliszack with us from **Safe n Simple**. Safe n Simple makes an assortment of high-quality ostomy accessories. Michelle discussed "Preventing Hernias" and talked about the new Safe n Simple hernia belts, as well as discussing all their other accessories. Peggy provided an informative discussion of hernias covering what they are, why they occur and how they are treated. Safe n Simple has a "Intro Kit" that includes samples of their products. To order a free sample kit: Phone **844-767-6334** ask for **Holly Loos**.

Regarding our wonderful CWOCN's, the Vacaville Kaiser still has not even listed the opening left by Mary Ann Chico. They are planning to do so, but we do not know when that will happen. In the meantime, **Peggy Terry** is graciously covering both meetings every month.

I am looking forward to when we can have physical meetings again. I am not sure when that will happen. I am leaving that decision up to Peggy as she is the expert concerning the health ramifications. I do not anticipate having meetings until August, but essentially, if all members at the meeting have had their vaccinations, it should be safe. We shall see. We may continue having video meetings once a month even after we restart in person meetings.

Upcoming Meetings – Add to Your Calendars – Details to Follow

April 1st - Hosts: Dan and Peggy, CWOCN
Roundtable Discussion and Q&A

April 15th – Hosts: Dan and Peggy, CWOCN
Potential Guest: Nancy Stevens, Byram Healthcare



AMAZING THE SUPPORT ONE GETS FROM A SUPPORT GROUP!

From: Ostomyconnection.com

Attending the first Ostomy Support Group may bring about many fears, questions and concerns. Overwhelmed with a new anatomy, there is so much to learn, and one may wonder if they are ready to discuss all that is on their minds and in their hearts. Recently, I spoke with a family who extolled praise for all their loved one learned, and the confidence it gave her to face her new normal.

My guess is that like other means of support, each person has their own medical story. For me, my ileostomy was the culmination of 23 years of suffering bowel obstructions, and it was my 23rd abdominal surgery. I was fortunate enough to awaken and believe a new life was in front of me. Most, however, do not feel the same. Many awaken after surgery to find themselves dealing with either a permanent or temporary means of their body ridding waste. Many are sick and don't even

have the time to deal with their new body because they can't take care of themselves. Rehab facilities and long hospitalizations may loom ahead.

Getting on one's feet to be well enough to attend a Support Group meeting may seem akin to "following the yellow brick road." "I will get there when I am well" may be a mantra. And yet, I have found that the Support Group truly helped me to "get well." So many questions, so much to consider, so frightened about the present and the future...all of that is overwhelming.



Support can look like many things. This wonderful family I referenced told me that they saw their Mom get dressed up for the outing, want to look her best to put forward her best. That determination brought with it great results... she became her best!

Recently, I began another Support Group and we had the proverbial one attendee, which was as it was for me last year when I began another group. She was a fireball and I have no doubt she will return next month. Our goal is to bring patients to the group, which is in the Medical Center, before they leave to begin their new life at home. We will be able to anticipate and answer their questions and concerns and provide a level of security that we are only a phone call away!

3

If you haven't joined a group, I encourage your participation. Regardless of how much you know, there is always more to learn, more to share, and more you can do to help others beginning on that yellow brick road!

Ask Nurse Coulter

Urostomy Rash

I have been a urostomate for six years. I have a skin rash that is raised, red and itching. It is not under the pouch, but about half an inch to the side and bottom. It's in patches of different shapes. Do you have any idea what it might be? Do I need to see a doctor or nurse?

MJ

Dear M.J.,

Thank you for including the location of the rash. Knowing whether the skin irritation is under the pouch or elsewhere helps determine the likely cause and treatment. If the redness and itching were underneath and matched the shape of the base-plate, it would indicate a product sensitivity and I'd recommend changing your pouch brand.

However, based on the description of the rash, raised, red, and itching, the most likely culprit is a fungal (yeast) rash. This is caused by an overgrowth of microorganisms that are naturally found on the skin. This happens when the skin is moist for a prolonged period, which can happen easily under or near an ostomy pouch, especially after a shower or any time you might sweat.

"After bathing or swimming, be sure to dry the skin under and around the pouch well."

To help clear the rash, first clean the area with a soap that doesn't contain fragrance or oil. Rinse and then dry the skin before applying an anti-fungal powder that contains **2% Miconazole**. Rub the powder in well. Since the rash is outside of the pouching surface, you can apply it two to three times per day.

These powders are available at most pharmacies, near the athlete foot remedies. Be sure to use a powder and not a cream or ointment, which can affect adhesion of your nearby pouch.

Since this rash happens when the skin is moist, you should also take steps to keep your skin dry. After bathing or swimming, be sure to dry the skin under and around the pouch well. A hair dryer on low heat for a few minutes should do the trick. Do the same if you do anything that causes perspiration like working out, yard work, or just being outside on a hot day. Using a **pouch cover made of cotton will help keep the skin under your pouch dry and prevent recurrence of the rash**. If you don't see an improvement, you should see your doctor. They can determine if eczema, psoriasis or another skin condition is causing the irritation and can prescribe appropriate medications.



What Are Some Examples of Skin Issues?

SKIN IRRITATION UNDER TAPE Irritated skin that develops only under the tape of your skin barrier can occur for a variety of reasons. The skin may be itchy, blistered or open and weeping. This problem can develop at any time, even if you have worn the same type of product for months or years. In this case, you may be sensitive to an ingredient in the tape, or your skin may have become damaged when tape is removed.

RASH AROUND A STOMA Sometimes a rash is caused by a skin infection or sensitivity, or even from leakage. The area may be red or red with bumps. Itching may also be a symptom. It is important to get assistance in determining the cause since the suggestions for treatment will vary.

LEAKAGES CAUSING IRRITATION Stoma discharge can be irritating to your skin, causing redness that can lead to open raw skin that weeps or even bleeds. This type of irritation is often very painful. (People with ileostomies are at the highest risk for this kind of skin damage.) A change in the size or shape of your stoma or the shape of your abdomen can change the fit of your pouching system, leading to leakage.

WHAT ARE SOME OF THE SOLUTIONS?

- Try a pouching system without tape. These products are adhesive but use a skin barrier instead of tape.
- Apply stoma powder to your skin before applying your new pouching system.
- Apply a liquid barrier film/protectant on top of the powder before applying the physical stoma wafer.
- Change your pouch promptly if drainage is leaking under the skin barrier.
- Change your pouch on a regular schedule before it leaks, generally every 3 days.
- Consider using accessories (convex skin barriers, paste, rings/seals) to help prevent leakage under the skin barrier.
- Contact your stoma care nurse if you are having difficulty keeping your skin barrier on.



Welcome to my fantasy.

By Ellyn Mantell

We all have our fantasies, so come along with me as I describe one of mine...new ostomates (those with ileostomy, colostomy or urostomy, all having had stoma surgery) would begin their adjustment to their new life with all of their questions answered, they would have knowledge and be welcomed into an [Ostomy Support Group](#), they would have a connection with a Wound, Ostomy, and Continence Nurse (WOCN) and they would recognize what a gift, what a lifesaver an ostomy is.



My concern is that this is not the usual for ostomates, either new or even those who have them for many years. In New Jersey, particularly where I live, there are many resources available, and yet, even in our sophisticated arena, many ostomates leave the hospital uninformed and underserved. Prior to Covid-19, I visited patients in the hospital or in rehab facilities to answer their questions. I brought journals and pens so they could write their emotions, concerns, and observations, and refer back to their notes as they made progress. I am so anxious to return to that important undertaking as soon as it is safe to do so.

When I had my surgery in March of 2014, my surgeon told me I would be in the hospital for 5-7 days. However, I felt so well, so quickly, that I was able to leave 4 days later. That was pushing the envelope, but I was so used to recovering from abdominal surgeries, having had 22 before that, my ability to go into recovery mode was well-entrenched. The majority of patients need so much more time, and now, even 4 days is more than they are offered.

Back to my fantasy, and my pipe dream of a great transition for new ostomates:

How can questions be answered, and knowledge gained as needed?

The majority of ostomies, even those performed in an emergent situation, require marking the abdomen for placement of the stoma (opening.) That is typically done by the [Wound, Ostomy, and Continence Nurse \(WOCN\)](#) and that is the person who comes to the patient's room post-op to begin to prepare the ostomate for life at home. In an ideal world, the WOC nurse has written information to share, which once home, will make more sense, and provides contact information for any questions. Additionally, the ostomate is put in touch with the United Ostomy Associations of America to become part of a bigger group of kindred people.

How do we find Ostomy Support Groups in our area?

I am involved in three [Support Groups](#), becoming president of one already formed when I had my ileostomy, and then worked with WOC nurses at two other hospitals in the area to form new ones. Until Covid hit, these were growing so nicely. But we are meeting virtually now, and staying as close as possible, knowing that the day will come when we are back together. It is wonderful to see "my people" who share my concerns, experiences and fears and accomplishments. We help each other in countless ways. People reach out to me through the WOC nurses in the area, United Ostomy Associations of America, [The Phoenix Magazine](#), the American Cancer Society, three hospitals, and through word of mouth. Because I am so open and revealing about my ileostomy and Lily, my stoma, I believe my name pops into the minds of people when they know someone in need.



Ostomies are Lifesavers! "Read all about it!" An ostomy provides the gift of health for many, many medical situations, including cancer, ulcerative colitis, Crohn's disease, diverticulitis, motility issues and devastating organ injury. We live in good times for our supplies and the ability to try new and innovative appliances and accessories. The Phoenix Magazine is a great resource for all, and assists in wading through the confusion many feel. Motivational stories and practical guidance round out the offerings.

A final word about those we call our Angels...the Wound and Ostomy Nurses.

Establish a relationship with one, and if there is an Ostomy Clinic or Ostomy Center in your area, use it! These nurses are your connection to properly-fitting appliances, the correct supplies and accessories, questions and personal support, as well as the ability to refer to a Support Group. More and more are entering the private sector and providing services such as home visits, particularly to those who cannot travel to a clinic or office, and your surgeon may even have one in the office to help navigate the transition to life as an ostomate. We call our WOC nurses our Angels, and that is exactly what they are, ladies and gentlemen with big wings to support us!

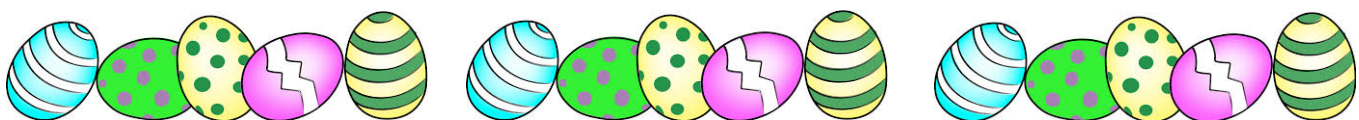
Ellyn Mantell is a UOAA advocate and Affiliated Support Group leader from New Jersey. You can follow her personal blog at [morethanmyostomy](#)

[These People Were Born with Rare Illnesses You've Probably Never Heard Of](#)

Knowledge brings understanding. Understanding brings awareness.

[Jenna Lee Fisher](#)

I know firsthand that living with a rare disease can be lonely. There just aren't the same resources available or enough awareness about the difficulties we face. This is why ostomates inspire us; they overcome almost impossible daily challenges to prove how much can be accomplished despite their limitations. These seven survivors might make up a small percentage of the population, but they deserve huge recognition.



Chelsea Wilson, born with Familial Adenomatous Polyposis

[Familial Adenomatous Polyposis](#) (FAP) is a rare hereditary condition that only affects 1 out of 10,000 people in the United States. FAP is characterized by hundreds to thousands of precancerous colorectal polyps that mostly affects the digestive system. Without surgery to remove the colon, people with Familial Adenomatous Polyposis will likely develop colon cancer. FAP should be managed by a doctor who knows this condition well.

One of Chelsea's biggest challenges is finding a doctor in Ohio who specializes in FAP. So instead of office visits, she meets with her physicians via phone and Skype. Every year, Chelsea has a colonoscopy to check if FAP has spread to other areas of her gastrointestinal tract. She also faces dietary challenges that vary from day-to-day. Living with this rare disease is not easy, but Chelsea is known for her “can do” attitude and uses her own experiences to advocate for more awareness.

Sarah Vasilakos, born with Chronic Intestinal Pseudo-obstruction

[Chronic intestinal pseudo-obstruction](#) (CIP) refers to a group of rare motility disorders, potentially disabling, where coordinated contractions (peristalsis) in the intestinal tract become altered and inefficient. Nerve or muscle problems cause the small and/or large intestine to lose the ability to contract and push food, fluid, stool, and air through the gastrointestinal tract. The cause of CIP is unknown, and there is no standard treatment because each case is very individualized. The main focus of CIP treatment is maintaining an adequate nutrition status.

Sarah had ileostomy surgery when she was only three weeks old, which was later made permanent at age nine. She has used IV fluids, total parenteral nutrition (TPN), and a gastric tube to help with nutritional deficiencies. Since the symptoms of CIP are so unpredictable, Sarah is constantly adapting to body changes that affect her daily life. Despite the challenges from this rare disease, she always has a smile, a positive attitude, and is dedicated to her job as a Registered Nurse at Inova Fairfax Hospital.



Melanie Nussbaum, born with Cloaca

A [Cloaca](#) malformation occurs when the urethra, vagina, and rectum are connected into a single channel, rather than three. The underlying cause is not known and occurs only in girls. Cloaca anatomy can vary widely, and the complexity of the surgical reconstruction also varies. These surgeries are done in stages, as they are so complicated that the best results are achieved when the baby is bigger.

Melanie was born with no intestinal or sphincter muscles because of Cloaca and lives with two ostomies. A Mitrofanoff, which was given to her 4-years-old and a colostomy, which she's had for the past 18 years. Being honest and open about her condition (even when it's not all good) helps educate others about this rare birth defect. She's been able to attend college, work with preschoolers, zipline, rock climb, travel, and so much more. She also volunteers as a certified ostomy visitor. Compassionate people like Melanie are the world's greatest treasures.

Chloe Moody, born with necrotizing enterocolitis

[Necrotizing enterocolitis](#), abbreviated NEC, is a devastating disease that affects a newborn's intestines. It typically occurs in premature infants, born less than 37 weeks, and is characterized by severe inflammation of a baby's small or large intestines, which may progress to tissue death. Surgical treatment is needed when there is evidence of bowel perforation. The exact cause of this disease is not fully understood but may be related to a premature intestine, abnormal gut microbial colonization, and intestinal inflammation.

Sometimes even full-term babies, like Chloe, develop necrotizing enterocolitis. As a result, she had colostomy surgery at birth and lives with short bowel syndrome. Her biggest challenge of living with NEC is maintaining adequate nutrition and living with chronic fatigue. But Chloe doesn't let that stop her from attending college, volunteering as a camp counselor at [Youth Rally](#), and advocating for NEC awareness. She's a true inspiration to the ostomy community!

Danielle McCormack, born with Imperforate Anus

[Imperforate anus](#) is a birth defect that appears to occur randomly for unknown reasons and characterized by the absence of the normal opening of the anus. Elimination of feces may not be possible until surgery is performed. In some cases, the rectum opens into the lower part of the vagina in females, or close to the scrotum in males. With surgical correction, normal elimination can become possible. Imperforate anus may occur as part of a malformation syndrome, such as [VACTERL association](#).

Danielle has lived with a rare illness her entire life and has been through more than 20 surgeries, including a colostomy when she was only one day old and reversed at the age of two. In 2014, she was given a temporary ileostomy which was later made permanent, but that didn't stop her from [modeling](#) for a lingerie company in the UK. She constantly strives to raise awareness and end the stigma associated with ostomies by sharing her story and inspiring others to "be confident and embrace what has saved your life." Danielle is truly a shining star.

When we think about bravery, we tend to picture heroes who face fear head-on. Heroic is exactly how I would describe every person living with a rare illness. If you think about it, real courage is when you do whatever it takes to save your own life every single day.

[Jenna Lee Fisher](#) Jenna Lee is a college student in Colorado studying sociology.

Ask Nurse Coulter

Irrigation Output

I have irrigated my stoma every day for the last 16 years. For the last couple of months I am having trouble getting stool out completely. Sometimes only a little comes out. I didn't change my diet, so I know that is not the problem.

P.T.

Dear P.T.,

Colostomy irrigation can provide a sense of freedom and security. I hope this has been the case for you. A change in diet can affect the regularity of our bowels. To help understand why only a small amount of stool comes out following irrigation, it's useful to know that the **main function of the colon is to absorb water from the food we eat and drink**. If you are not well hydrated when you perform the irrigation, your colon will absorb some of the water that is used for the irrigation. This results in less return of fluid and stool than you would have when you are well hydrated.

To be sure you are well hydrated, drink a glass of glass of water before you irrigate. This will help your irrigation be more effective. To stay hydrated, drink fluids with electrolytes and **low sugar** every day. During hot summer months or in a warm, dry climate, you will need to drink more than this. Remember that **caffeinated and alcoholic beverages do not help maintain good hydration**. Some medications can also affect hydration. Diuretics, often called "water pills," used to treat high blood pressure, heart failure, glaucoma, kidney failure and edema will make you urinate more and be less hydrated. If you are on a diuretic, ask your physician if it is okay to take the medication after you irrigate your colostomy.



Interesting Product for Discrete Pouch Change & Disposal While on the Go?

About

People with an ostomy often find themselves in places where changing their pouch can be very uncomfortable and embarrassing. Even worse, many ostomates just avoid doing activities or going places that they enjoyed prior to having an ostomy. With the Ostomy Pouch Disposal Seal pouch changes can be made virtually anywhere, hygienically, efficiently and discreetly. www.ostolutions.com

Features & Benefits - Video: <https://youtu.be/jDNyyiRz Ms>

The **Ostomy Pouch Disposal Seal** will enhance your life with these benefits:

- **Confidence:** Odor-proof disposal allows pouch to be discarded immediately or at a future point.
- **Discretion:** Odor-proof means better concealment of a pouch change.
- **Simplicity:** Ostomy pouch change in less than 20 seconds. Less time = less odor.
- **Flexibility:** Ostomy pouch changes in any private setting, standing or sitting, without the need for a toilet.



"Up to 80% of Crohn's patients may require some sort of surgical intervention with at least 10% requiring a permanent stoma. In ulcerative colitis, 10-30% of patients may require entire removal of the colon." - Phoenix Magazine Spring 2021



"Good news. The pain in your chest wasn't a heart attack. It was your belt buckle."



SOLANO CHAPTER DIRECTORY

OFFICERS AND BOARD MEMBERS

DAN BRUCE, LEAD COORDINATOR...530-979-7772
OPEN, CO-COORDINATOR...

MEDICAL ADVISORS

ANDREW CHAE, MD
KAISER/VALLEJO

DAN BRUCE, TREASURER.....530-979-7772

FRANK JOHNSON, BD MEMBER.....448-5853
"KATS" YAMAMOTO, BD MEMBER...745-4441

RN - ET NURSE'S

PEGGY TERRY, C.W.O.C.N.
KAISER VALLEJO
MARY ANN CHICO
C.W.O.C.N.
KAISER VACAVILLE



COMMITTEE CHAIRPERSONS

VISITATIONS: OPEN.....

PROGRAM CHAIR: OPEN.....

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

BEVERAGE SERVICE: OPEN.....

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.

**MEMBERSHIP APPLICATION
(MAKE CHECKS PAYABLE TO OSTOMY ASSOC OF SOLANO)
MAIL TO O.A.S., P.O. BOX 5142, VACAVILLE, CA 95696**

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.

