



**Jacksonville Meeting
Safe N Simple Representative
Joining March 19th Meeting**



Beth Peter from **Safe n Simple** will be hosting the March 19th ostomy support group meeting.

Product highlights will include:



Skin Barrier Sheet Plus with aloe and zinc oxide:

Safe n Simple took the original hydrocolloid skin barrier sheet formula then added aloe and zinc oxide. Aloe and zinc oxide both have healing properties that promote skin health. This sheet is used to protect the skin from output, and is highly absorbent, in addition to promoting skin health for irritated skin. Apply directly to the peristomal skin. Cut to fit around the stoma- no starter hole.

Samples will be provided by Safe n Simple of the Skin Barrier Sheet Plus, Skin Barrier Ring Conforming Seal-Extra Thick, and 2" Dermapro Waterproof Silicone Tape.

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Ostomy Discounts offers ostomy supplies at great prices to uninsured or underinsured ostomates:

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Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel

Find all the past issues of the MailBag at <http://ostomymcp.com/id6.html>

**Jacksonville
Contact Information:**

Patti Langenbach

(800) 741-0110

(904) 733-8500

patti@ostomymcp.com

Support group meets the 3rd Sunday of each month 3 p.m.

4836 Victor Street

Next Meeting: **March 19th**

Also join us by Zoom

[https://us06web.zoom.us/j/](https://us06web.zoom.us/j/94640600811)

[94640600811](https://us06web.zoom.us/j/94640600811)

Meeting ID: 946 4060 0811

or call +1 301 715 8592 US

**Gainesville Support Group
Contact info:**

JoAnne Bell at 352-284-4214

Meets the 1st Sunday of each month (except Holidays)

at Hope Lodge 2121 SW 16th St

Gainesville, FL

Next meeting: **TBA**

Ocala Support Contact info:

Karen Franco 352-304-1309

Meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street between Ocala and Belleview.

Next Meeting: **TBA**

**Citrus County Support Group
Has Disbanded**

To find a support group

in your area visit:

<https://www.ostomy.org/support-group-finder/>

**Amelia Island Area
Ostomy Support Group**

(904) 310-9054

Meets second Monday of each month

at 6:30pm

Next Meeting: **TBA**

The Villages Ostomy Support

We meet on the 2nd Tuesday evening of each month at 6:00 PM at (except

July & August

Linda Manson

tvostomy@gmail.com

865-335-6330

Next meeting -**March 14th** @ 6 pm
Saddlebrook Rec Center (near Polo Field)

Masks Required

Contact Linda tvostomy@gmail.com

Celebrating St Patrick's Day with an Ostomy from NSA Ostomy Support Group



Everyone loves St Patrick's Day- at least those of us with Irish names like to believe that.

Ireland is one of my favorite destinations. We have family there and love the warmth of the people, and the beauty of the countryside. My husband has dual citizenship and is working to learn Irish. I love St. Patrick's Day and want everyone to have a great time celebrating.

Holidays are tied to traditional foods and drinks. If you have an ostomy, this can pose some questions regarding what you can eat and drink. With an established colostomy, you can eat anything that you want but there is a price to pay with certain foods. A classic St Patrick's day dish, corned beef and cabbage may result in more gas than you would like. A better choice might be Shepherd's Pie or a rich beef stew with Guinness. Cabbage can be more difficult to digest and needs to be completely cooked and cut into smaller pieces for those with an ileostomy. As with any food, portions need to be appropriately sized and properly chewed. Another staple is Irish Soda

Bread. It is fine to eat with the Guinness stew but again, a limited portion is advised. It will thicken output.

The BIG question is always, "Can I drink alcohol with an ostomy?" Life is about moderation. Having an ostomy is about living life to the fullest but the more you know, the better prepared you are. Even a true Irishman should temper their intake. Normal alcohol consumption is 2 drinks for a woman and 3 for a man. They should be spaced out over the span of hours. It goes without saying that there should be NO DRIVING when drinking and NO DRINKING WITH A NUMBER OF MEDICATIONS LIKE NARCOTICS. In addition if you have any medical condition or addiction, alcohol should be avoided.

Having the facts and being prepared are key to an enjoyable evening with friends. If you plan on imbibing with a drink or two with friends, it is advisable not to drink on an empty stomach. Certain starchy foods will help "soak up" some of the alcohol and should be eaten BEFORE drinking. Snacking on breads or pretzels can be helpful while you are 6 NWA Ostomy Support Group - A UOAA Affiliate MARCH 2021 drinking. Another trick is to look at additions to help balance out electrolytes. Bananas or strawberries added to a blender drink like daiquiris or margaritas will add a bit of balance to what you are drinking but again, moderation is the key.

Choosing what to drink is important. Regardless of whether yours is a colostomy, ileostomy or urostomy, you need to realize that ALL alcohol acts like a diuretic. A good rule of thumb is to drink 8 oz of water with every drink you consume. If you have an ileostomy, you have to be especially careful to maintain hydration. You might pack electrolyte tablets for that evening out and add one to the glass of water you are going to drink between each drink. Drinking certain beverages may cause your pouches to fill very quickly. Plan on emptying that urostomy pouch more frequently- even if you have a leg bag. Ileostomy patients may want to include that gelling sachet (Parsorb, Diamonds, Pearls, Ileosorb) into their pouch each time the bag is emptied. Everyone with an ostomy should ALWAYS have their kit for an emergency change with them at all times but especially for that night out.

What you drink does make a difference. If your preference is green beer to toast St Patrick, keep in mind that beer, even Guinness, is made with hops and will lead to increased gas.

An Ostomy Turned This Pro Athlete Into a UC Advocate

by [Jackie Zimmerman](#) Patient Advocate



HAVING [ulcerative colitis \(UC\)](#) in the '70s almost prevented Rolf Benirschke from going on to become the all-time scoring leader of the San Diego Chargers — as much for the hospitalization it caused as for the cultural taboo around the pouch attached at his abdomen, there for bodily waste to pass through, called an ostomy.

After his recovery, Rolf had to navigate his new life with an ostomy and figure out how to play football again. He got back in the game, but he didn't stop there — Rolf became a vocal advocate for IBD, helping to fight the taboo and normalize ostomies.

HealthCentral talked to Rolf about his journey as an athlete with UC and how he made it his goal to battle ostomy stigma and connect with other patients.

HealthCentral (HC): You were among the first professional athletes to play openly with an ostomy. How did you make the choice to share your story with the public?

Rolf Benirschke: Yes, I was the first professional athlete to wear an ostomy appliance while playing. It was especially noteworthy given that football is such a physical sport. I was very reluctant to share publicly the exact details of my operations. I was happy to talk about IBD and surgery and the long and difficult recovery, but I would always stop short of saying I was now wearing appliances. It wasn't until I was partway through my comeback season of 1979 that I made the decision to open up about it, and only then because a nosy reporter forced the issue in a live interview. I was a little uncomfortable revealing everything because I was single and not sure how that would be received and, let's face it, bathroom issues are not exactly dinner table conversations.

Rolf Benirschke



HC: Was your place in the NFL ever at risk because of your UC or later because of your ostomy?

Rolf: When I returned to the team to try to earn my job back the next July in training camp [after my surgery], few people knew I was wearing ostomy bags. They all knew I had had surgery but didn't understand the specifics.

I never expected to play again. Football was never a thought... it was initially just trying to recover and figure life out. At the time, in 1979, few people were talking about IBD and nobody was open about ostomy surgery.

HC: What was the response like after you shared your ostomy with the world?

Rolf: That first year back, because of the visibility of the NFL, there was a lot of interest in my comeback and, on almost every away game, the local sportswriter or TV anchor would do a story about what I had gone through with UC. There was a tremendous amount of support sent my way via letters, flowers, prayers, and more during my hospitalization. Wherever those stories appeared, patients or family members of patients would read them, and many would write me a letter and I would find them piled in my locker the next week.

One of the biggest guys on the team came up and shared that his mother had an ostomy, and I remember him saying, "Man, you've got guts to keep playing," to which I tried to lighten the situation by saying, "Well, not as many guts as I used to have." He was wonderfully supportive and that cleared the way for other teammates to come up and ask questions and try to understand.

"One of the biggest guys on the team came up and shared that his mother had an ostomy, and I remember him saying, 'Man, you've got guts to keep playing,' to which I tried to lighten the situation by saying, 'Well, not as many guts as I used to have.'" — Rolf Benirschke

HC: You have an impressive resume in advocacy. What are you doing now on the advocacy front?

Rolf: Nine years ago, I took a leap of faith and started a patient engagement health care company to assist pharmaceutical and medical device companies better engage with their patients. We might've been a little ahead of things then, but now every stakeholder in health care needs to understand and better connect with their patients. To do that, they need to understand how we patients think, answer the four unspoken question I believe every patient asks but doesn't articulate, and understand we are "consumers" now who are more informed and connected with other patients than ever before... and we want to be involved in our healthcare.

Since I consider myself the most grateful patient, I wanted to create a community of grateful patients like myself to share their stories and encourage one another, so I founded the [Grateful Patient Project](#) and the [Grateful Ostomate](#). It brings me great joy to be able to share those stories within the medical community with pharmaceutical companies, medical device companies, medical professionals, hospital systems, and others.

Rolf Benirschke

HC: What are you most proud of in regards to your advocacy?

Rolf: While it was a little difficult at first for me to really open up about my ostomy, pretty soon it became a mission and a calling and it changed the course of my life. There has been nothing quite as fulfilling as being able to connect with a patient when they are in the throes of their illness and facing surgery, encourage them and maybe send along my autobiography, "[Alive & Kicking](#)," or one of the other ostomy story books I have written, and then hearing back from them months later when they are back to doing what they never thought they would be able to do again.

There are a lot of things I am excited about and appreciative of from having walked on the Hill numerous times, speaking before Congress on hepatitis C issues, working with colorectal surgeons and wound, ostomy, and continence nurses to change the way ostomy appliances were classified and more. But the thing that still drives me the most is connecting with individual patient and encouraging them along the way.

[Interview has been condensed and edited by Health Central.]

A FEW INTERESTING UROSTOMY FACTS! source: Ostomy Fredericton summer 2018

- Mucous in the urine is normal. The ileal conduit is made of mucous-secreting intestinal tissue. It doesn't stop doing its job even though it is transporting urine.
- If it is necessary to have a urinalysis, remind the nurse to take the specimen directly from the stoma, not from the pouch.
- Deodorants are not used because they may mask the odor which could signify the presence of an infection.
- Carbonated beverages make urine alkaline, so stick with cranberry juice.
- Water is useful to reduce the likelihood of a kidney or bladder infection.
- Orange juice is not used by the body as an acid, but as an alkaline.
- Change your pouching system first thing in the morning before eating or drinking.
- Rinse off or wipe off the spout of the pouch after emptying to prevent urine odor on underclothes.
- Wearing clean pouches and frequent emptying are vital. Adequate fluid intake, particularly fluids that acidify the urine, decrease problem odor.

UOAA's 8th National Conference-Postponed

AUGUST 10, 2023 - AUGUST 13, 2023

<https://www.ostomy.org/event/uoaa-8th-national-conference/>

Visit the Peristomal Skin Assessment Guide for Consumers

<http://psag-consumer.wocn.org/#home>

UOAA COVID-19 UPDATES

UOAA will update this blog post with any information that may affect our community.

<https://www.ostomy.org/coronavirus-effects-on-the-ostomy-community/>



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