

The Ostomy Support Newsletter Of Jacksonville, Ocala, Amelia Island, Gainesville, & The Villages



The Ostomy Clothing Company

https://ostomyclothingcompany.com/

Our mission is to strive to continually develop and advance our products that are suitable for a Colostomy, an Ileostomy or a Urostomy. Many of our products are adaptable for those who have two ostomies. As a fellow Ostomate, I am well aware of the inconveniences and the major changes that having an ostomy makes in our lives. Clothing does not need to add to our stress.

My personal mission is to try to sincerely assist my customers in trying to retain as much comfort and "normal" day-to-day life experiences. I believe that wearing clothes that help you be comfortable and supported is the first step in living your life to its fullest.

As my wife once wisely said,

This stoma does not need to define who you are.

Les Coulter

Shop

- Our Store https://ostomyclothingcompany.com/our-store/
- Ostomy Support Body Wraps https://ostomyclothingcompany.com/ourstore/body-wrap/
- Ostomy Support Underwear https://ostomyclothingcompany.com/our-store/ underwear/
- Ostomy Support Accessories https://ostomyclothingcompany.com/our-store/ accessories/
- Ostomy Support Cummerbunds https://ostomyclothingcompany.com/ourstore/cummerbunds/
- Ostomy Hernia Support Belts https://ostomyclothingcompany.com/ourstore/pouch-cover/
- Ostomy Seatbelt Protector https://ostomyclothingcompany.com/our-store/ seatbelt-protector/
- <u>Shower Buddy</u> https://ostomyclothingcompany.com/our-store/shower-buddy/

Jacksonville Contact Information:

Patti Langenbach (800) 741-0110 (904) 733-8500

mcp@ostomymcp.com Support group meets the 3rd Sunday

of each month 3 p.m. 4836 Victor Street Next Meeting: August 18th

Also join us by Zoom https://us06web.zoom.us/j/ 94640600811

Meeting ID: 946 4060 0811 or call +1 301 715 8592 US

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 **Sept. 10th** @ 6 pm Saddlebrook Rec Center (near Polo Field)

Masks Required Contact Linda

tvostomy@gmail.com

Visit the Peristomal Skin Assessment Guide for Consumers

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

UOAA Discussion Board

https://www.uoaa.org/forum/ index.php

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

Medical Care Products, Inc.

(904) 733-8500 (800) 741-0110

http://www.ostomymcp.com



From the Stage...to Ostomy Surgery...to the Big Screen via UOAA E-News June 2024 and UOAA Blog Post

Short Film Inspired by Ostomate Set to Premiere at a Los Angeles Film Festival

Written by Raimo Strangis



My ostomy journey began back in 2004. I was in my early 20's and the frontman of a rock band, called Cranney. We started gaining a little buzz in the Toronto rock scene, playing all the historic venues like El Mocambo, Lee's Palace, and the Horseshoe Tavern. Things were going great. Then, I started feeling really sick, but I ignored it. Finally, I went to the doctor and was diagnosed with ulcerative colitis. I had never heard of it. At first it was manageable; some stomach cramping and urgent bathroom runs. Medication was working and Imodium was my best friend. Suddenly, my condition got much worse. The urgency, blood, and cramping would come on like an avalanche. I exhausted all the medication options, and nothing was working,

except for steroids, which is not a longterm solution. I lost a lot of weight and would plan my routes knowing where the best public bathrooms were. Every time I entered a building, I immediately needed to know where the washrooms were. There were days when I wouldn't leave my room, let alone my house. I canceled shows, stopped going out with my friends, and skipped family outings. This behavior turned into depression and anxiety, eventually ending the band and my musical career. I felt like I lost my purpose, which led to some dark nights and even darker thoughts.

My doctors recommended ostomy surgery. I had never heard of that either. After doing some research and being young and naive, I said there's no way I'm doing that. So, I suffered for ten long years. Finally, in 2014, in my 30's, married and with two kids, I decided to have ostomy surgery. It was the best decision I've ever made. No more pain, suffering, or worrying about bathrooms. I was free to live my life again and I didn't care what people thought.

It's easy to look back now and say, I should have just had the surgery sooner, I could have kept playing music. But when you're in the moment, faced with a life-altering surgery, the fear, shock, and hopelessness is blinding. With no examples or stories of people going through the same struggles, I felt alone. This is where I knew an important story needed to be told.

In 2020, I wrote a book titled, With Little Means. In the book, I tell a story of an aspiring musician who gave up on his dreams after ostomy surgery. The book fell into the hands of actor/producer Micheal Pillarella. He was moved by the story and felt it had potential to make an inspiring film. Together, we began working on an early version of a script.

Then, we knew we needed a great director to bring our story to life. Dan Abramovici is an award-winning writer/director, with his films being featured in acclaimed film festivals around the world. Dan's vision was not your typical PSA, but an honest, real, film festival worthy short film. Once Dan and fellow screenwriter Liam Gareau, took over the script writing duties, a compelling story began to unfold.

Next, we needed a film production company to put it all together, that was Stagg Forrest Films. With a combined passion for storytelling and a wealth of experience, Myrthin Stagg and Kate Forrest were committed to creating an engaging and thought-provoking film that would resonate with audiences worldwide.

Then, we needed a cast of talented actors. Once Michael committed to the lead role of Rai, and actress Karen Knox came onboard to play the eccentric bandmate Isla, we knew we had the right actors to deliver a compelling performance.



Finally, we felt it was important to have the support of an organization that shared our vision and belief in the cause. Being a member of an ostomy support group, Barrie branch, I knew who I needed to contact, Ostomy Canada Society. John Hartman, recently retired and former Executive Director of OCS, from our first conversation, felt a strong connection to the story and was excited to get involved. Thus, a short film was born, Stuck.

The film captures a pivotal moment in time. Rai, a musician who just had ostomy surgery, is isolating at home struggling to come to terms with his new reality.

Haunted by his deepest fears, he's given up on his music career. Enter Isla, his eccentric ex-bandmate. She's there because she desperately needs him to play a show that night, but also because she cares. The conversation escalates, and Rai says things he wishes he hadn't, pushing Isla away. He's afraid to get back on stage. After a moment of reflection, Rai grabs his guitar and begins to play for the first time in a long time. Will he play the show that night? We don't know. But at least he's picked up the guitar and is playing music again.

The short film will have its world premiere in Hollywood, California at the historic Chinese Theater on Sunday June 23, 2024, at 2:45pm, as part of the Dances With Films festival. The film will be submitted to international film festivals around the world.

I hope by telling a story like this we can bring comfort to those who may be suffering as I did. I thought having ostomy surgery would ruin my life, but instead it gave me my life back. Please join us on this special day as we celebrate a film that features a character living with an ostomy.

Doctors Do the Prescribing but You Need to Take Charge! via UOAA Update and St. Louis (MO) Live and Learn

- Be curious
- Know what your condition is and how the drug will help you
- Don't play doctor
- Never tinker with the dosage on your own
- Share your life story. The doctor needs a complete picture of your health and habits and make friends with your pharmacist. You can never get too much information. Plan a review session every 6 months
- One in five Americans over 65 takes at least one inappropriate prescription drug. One size doesn't fit all
- The amount of medicine you need may vary with age, weight, gender and ethnicity. Send old drugs packing
- Review your medicines at least once a year and get rid of oldies that are no longer goodies. Timing is everything
- Some side effects can be avoided by adjusting the timing—but ask your doctor before changing. Be aware of interactions. Drug-Herb, Drug-Drug, Drug-Condition, or Drug-Food are all potential interactions.



The Value of Intimate Conversation by Ellyn Mantell, morethanmyostomy.com; via UOAA Articles to Share, April 2024

Our Ostomy Support Group has become a wonderful source of comfort, education, and positivity over the years. We are cohesive and I am proud to say that I have personally spoken with, or had contact with, each and every member at one time or another. In our one-on-one establishing of rapport, we discuss everything on the mind of the ostomate, some things more personal than others. Opening up in the group is more difficult, and I am not referring to anything specific, including "under the covers" conversation. Just being able to say, "This is how I feel..." is a privilege we all appreciate.

At our monthly meeting last week, one of our members said, "Although it is the end of the meeting, I just have to say that sometimes, I am sad when I look at myself." We all stopped, and I saw faces change, look at the screen and actually acknowledge, in unison, "Yes, I feel that way at times." I realized that in being a cheerleader, always attempting to put a positive face on ostomy or other challenges, I had neglected to leave space for sadness.

There is sadness when we feel our bodies have betrayed us. We can tell ourselves how fortunate we are...and WE ARE!!! but, we can be sad. As one of the ostomates pointed out, gratitude and grieving can happen simultaneously. Even a decade later, I can remember leaving the shower the day I returned home from my ileostomy and looking at myself in the mirror. "Oh, my G-d, how will I ever look at myself again?" I cried and I cried, knelt on the floor, and couldn't lift myself to dry. Bruce came into the bathroom and saw a woman in extremis, miserable and humiliated. He held me and I sobbed, asking him how he could look at me? He told me that he was very proud of me, that he loved me. I gave myself permission to grieve and then, with infinite gratitude for this lifesaving surgery, I put on my nightgown and slept.

I am so proud of our group, for many reasons, not the least of which is that going deep in our feelings is a way to truly connect, to truly understand, and to truly be with another. The value of intimate conversation is that the other person knows that another has experienced or is, even now, experiencing the same emotions and reactions as they.

When people ask me why they should attend a support group of any kind, I simply reply "People need people!" And I would like to add to that, we need others to share confidences, acknowledge they are not alone, and to simply say, "Yes, I have been there, felt that, understand." If you need support, please reach out. There truly is nothing new under the sun, and if you are experiencing grief, you may just feel gratitude, as well.



OSTOMY AWARENESS DAY Saturday, October 5, 2024

Check here https://www.ostomy.org/ostomy-awareness-day/ often for information on this year's National Ostomy Awareness Day on Saturday, October 5, 2024.



TIPS FOR THE UROSTOMATE SOURCE: UOAA Update

Check the pH of your urine about twice a week to be sure the urine is acidic with a pH of less than 6.0.

Always wash your hands before working with your appliance or stoma to avoid introducing bacteria into the stoma.

Reusable or disposable appliances that are not cleaned adequately or are worn for long periods of time can cause urinary tract infections from bacterial growth in the pouch and urine.

Signs and symptoms of a urinary tract infection included fever, chills, bloody urine, cloudy or strong-smelling urine, and pain in the back kidney area.

If you experience these symptoms, see your doctor.



https://myadvancedwound.com/

AIRTRAVELTIPS FROM UOAAAND THE TSA

https://www.ostomy.org/ostomy-travel-and-tsacommunication-card/

UOAA'S 8TH NATIONAL CONFERENCE

Announcement: The 2025 UOAA National Conference will be August 14-16 2025 in Orlando, Florida at the Hyatt Regency Grand Cypress Resort. Check back later for more information on a special hotel rate and program information.

Thank you to all the attendees, sponsors, speakers, exhibitors and volunteers at our 8th National Conference held August 10-12, 2023 in Houston, Texas! UOAA National Conferences are held every two years so details about the next gathering in 2025 will be shared when available. Check out the recap video below for a peak at the conference experience.

https://www.ostomy.org/wp-content/uploads/ 2023/07/8th-National-UOAA-Conference_Program-Schedule_07182023.pdf

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To: