UOAA United Ostomy Associations of America, Inc.

The MailBag

December 2018

The Ostomy Support Newsletter Of Jacksonville, Amelia Island, Citrus County Support Group & Gainesville Ocala

**Join Us December 16, 2018.
The Jax group is holding our
Christmas party at Patti's house again.
3pm and call 904-733-8500 for address
and directions.**

Medical Care Products, Inc.
(904) 733-8500
(800) 741-0110

Check Out The MailBag Now On FaceBook
https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel

**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: **Dec 16th
Christmas Party
at Patti's house.
Must call for directions.
904 733-8500**

**Gainesville Support Group
Contact info:**
Brinda Watson (352) 373-1266
Jean Haskins (352) 495-2626
Meets the 1st Sunday of each month
(except Holidays)
at Hope Lodge2121 SW 16th St
Gainesville, FL
Next meeting: **Dec 2nd**

**Ocala Support
Contact info:**
Lynn Parsons 252 337-5097
www.ostomyocala.com
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: **Dec 9th**

Citrus County Support Group
Meets third Sunday of each month at
2:00 PM in the Seven Rivers Regional
Medical Center, 6201 N. Suncoast
Blvd., Crystal River, FL 34428, in the
Community Room of the Medical
Office Building
Next Meeting: **Dec 16th**

**Amelia Island Area
Ostomy Support Group**
(904) 310-9054
Meets second Monday of each month
at 6:30pm UF North Campus
UF Health North 15255 Max Leggett
ParkwayJacksonville, FL 32218
(Meeting Room 3-4)
Free parking
Next Meeting: **Dec 10th**

“Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories’!”

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

DAWNETTE/DAISY’S story: “Awesome Ollie Teddy Bear: Inspiring, educating, and empowering children (and adults)” by Dawnette Meredith:

“What you see on the news may lead you to believe the world is an unfriendly and uncaring place, but the map on my wall tells a much different story.

In December of 2015, I was home recovering from ostomy surgery. A lifelong, painful battle with severe colonic inertia and countless unsuccessful medications and treatments had left me no other options. Surrounded by a supportive and loving family, I still felt alone and isolated. I rested in bed and scoured the internet for encouragement and connection to people “like me.” Two discoveries that day sparked an unexpected passion and purpose for myself and many others.

First, on my screen, from halfway across the world, was a very special bunny – a bunny with an ostomy. I don’t care for stuffed animals, but I had to have him. A small fortune later, the bunny arrived on my doorstep. When I opened the package, the flood of emotion surprised me. I can only explain it as comfort and joy with a few giggles mixed in. It was in that moment that I understood why I was compelled to buy him. He was the first “ostomate” I’d ever met.

I couldn’t wait to show the bunny to my family and close friends. It began to soften my uneasy feelings about having an ostomy by providing a vehicle of conversation. I’m a grown woman, but a stuffed animal opened the door for me to positively cope with the reality of living with an ostomy for the rest of my life.

The second important discovery was finding a United Ostomy Associations of America Affiliated Support Group near my home. I’d never been to a support group of any kind, and frankly, I was feeling okay as a new ostomate – I didn’t need “support.”

Boy was I WRONG! I walked in the room and saw normal, everyday people chatting and enjoying life. Without speaking even a word, every person in the room that day encouraged my soul. In the months following, I deeply valued their support as I learned to navigate and thrive as an ostomate. They became my friends.

It was October of 2016 when these two events merged and sparked a movement. I discovered the children’s hospital near my home performs around 120 ostomy surgeries per year. If a grown woman was encouraged by a stuffed animal with an ostomy, how much more would a child? Soon I designed a teddy bear with a stoma and removable ostomy pouch and approached my UOAA support group with the idea of sponsoring ostomy teddy bears for all 120 pediatric ostomy patients at the local children’s hospital. The response was overwhelming and the Awesome Ollie Teddy Bear Project was launched!

Thanks to members’ ongoing monthly support, and a gift from Shield Healthcare, the Ostomy Support Group of San Diego County continues to gift hundreds of ostomy Teddy Bears to children at Rady Children’s hospital. The bears are given to the pediatric ostomy nurses and the child life specialists at the hospital who present the bears to their patients for comfort and education.

A short year later, other UOAA support groups, WOCN Society affiliates, The Phoenix magazine and other individuals have expanded the project in order to gift Awesome Ollie Teddy Bears to children with ostomies in their communities. 11 Health Technologies gave away 200 Ollie Bears to adult attendees at the UOAA National Conference in Irvine, CA, causing quite a stir! News of Ollie’s advocacy spread and people from all over the United States sent me their stories about receiving an Ollie bear.

A mom with an ostomy contacted me through social media and requested a bear for her four-year old daughter, who was very curious and interested in her Mom's ostomy. Another child, just two months old, received an Ollie Bear while he recovered in the hospital after his ostomy surgery. His mother found Ollie while scouring the internet looking for hope and encouragement. Then a long-lost friend from high school who lives 2,000 miles away purchased a bear prior to undergoing her own ostomy surgery. Even the cancer center near my home called and asked for an Ollie bear for one of their adult patients. Age is irrelevant to the need for comfort, connection and encouragement.

So what does a map have to do with any of this? A giant wall map hangs in my home. It's a visual reminder of the places Awesome Ollies have been sent and a testament to all his caring compassionate sponsors. It's covered with stickers from coast to coast and Canada. It's an expression of the power of a handful of positive everyday people who took action to help someone else. The media suggests that our country is increasingly unfriendly and uncaring. To me, my map is proof otherwise.

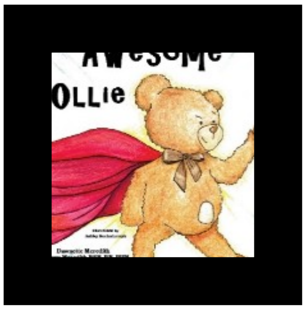
Thanks to the help and advice of pediatric WOCN's and child life specialists, my daughter and I wrote a children's book about Ollie and his Awesome Ostomy, intended to inspire and empower children with ostomies. It is scheduled to be released Spring/Summer 2018.

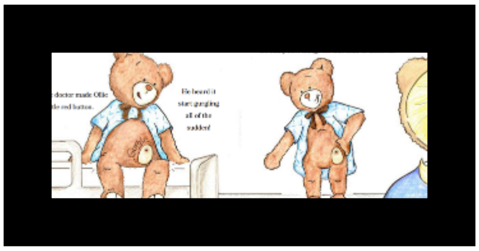
To organize Awesome Ollie Teddy Bears for your community hospital or to inquire about the children's book, visit AwesomeOstomy.com or email Terrabusy@ yahoo.com. Follow all the new places Ollie is sent on the AwesomeOstomy Facebook page.

Special thanks to the Ostomy Support Group of San Diego County, whose vision and generosity sparked an international movement of hope and compassion."

Dawnette's article appeared in Spring 2018 US Phoenix ostomy mag, p. 68-69…

PHOTOS: prepping Awesome Ollie Teddy Bear for his literary "debut:"





Awesome Ollie Teddy Bear doing his "job" to help little girl recipient cope with her ostomy in hospital; several "cuddled" by medical professional:

Dawnette/Daisy:

Friends with Awesome Ollie Teddy Bears:

“WOCN Society and the UOAA – Renewed Partnership Needed.

By Dawnette Meredith

Meeting the complex physical, psychological, and lifestyle needs of new ostomy patients is a monumental goal, one that I hope will inspire a renewed partnership between the two most prominent forces in the realm of ostomy care and advocacy - the WOCN Society and the UOAA. There has been a longstanding relationship between these organizations, but the landscape of patient care is changing - so must the collaboration of these two great organizations.

I had ostomy surgery in December 2015. The highly-advanced robotic surgery left me with barely-noticeable incisions and a permanent colostomy. My surgery was a medical and technical “win,” but helping me live with the surgery was initially a losing proposition. My hospital stay was only two nights and three days. Although a capable ostomy nurse visited me once in the hospital and spent 20-30 minutes teaching me basic ostomy care, I have to admit the details were lost due to the pain medications and the overwhelming amount of information provided. I arrived home feeling scared, isolated and overwhelmed with my new way of life. Questions flooded my mind. How do I go back to work, travel, dress and swim? How do I actually LIVE with my permanent colostomy?

Many studies published in the Journal of Wound, Ostomy, Continent Nursing (JWOCN) acknowledge gaps in meeting patient needs, much like what I experienced. But despite their heroic efforts, WOCN’s (Wound, Ostomy, and Continence Nurses) are put in the difficult position of trying to educate and equip new ostomy patients in ever-shrinking time frames

and insurance limits. It’s impossible to adequately educate patients on basic self-care, to address isolating lifestyle issues, and to connect patients with valuable resources with so little time. One study, titled Bridging the Gap * noted that patients ranked “ostomy self-care” and “information on resuming activities of daily living” as the two most useful categories for recovery. As an ostomate myself, I strongly concur. Ostomy self-care is *only half of the recovery process and learning to return to everyday life is the vital second component.* As a patient advocate, I receive calls and email questions from ostomates, desperately needing information on how to leave their house to go shopping without fear, how to manage airport security and whether they can “do any of the things they can enjoyed in the past.” A collaboration between the UOAA and the WOCN Society would create a larger voice to set these ostomates free!

“It is time to give the ostomates what they so desperately want: a holistic and well- rounded approach to ostomy living that combines the best of the medical/practical side as well as the lifestyle/psychosocial aspects of life with an ostomy.”

And what makes me wonder is… the hospital where my ostomy surgery was performed currently holds patient education classes for diabetes, COPD, cardiac rehabilitation, weight control, spinal cord injury, hearing loss, tobacco cessation, arthritis, anticoagulation and more, but where are the classes for ostomy patients? Patient education classes have been shown to decrease hospitalizations, improve quality of life, lower health costs and improve clinical outcomes. These classes benefit the patient and the hospital, but right now, ostomy patients are visiting our emergency departments asking basic ostomy questions and requesting supplies simply because the information and support for this demographic isn't readily available. The UOAA strives to empower and educate ostomates on lifestyle issues but, unfortunately, current patient privacy regulations have made it difficult for the UOAA to connect new ostomates to lifestyle resources and support them through their Patient Visitor Programs. The UOAA national and local affiliated groups receive thousands of calls from patients desperate for help and information, further demonstating the “gap in care.” It is time for these barriers to be broken, and for new programs to be developed in order to set new ostomates up for success.

With all of this in mind, I believe that the WOCN Society and the UOAA are perfectly poised to embark on a cost effective, powerfully impactful partnership to equip ostomates to live more successfully. First, I propose a collaboration to develop a “Lifestyle Class” curriculum to be implemented in a hospital setting by trained, certified UOAA volunteers and supervised by a WOCN. The UOAA would build upon their current Patient Visitor's Program to train and effectively equip volunteers to lead classes across the country for very little cost. Short informational videos and other educational materials could be created to standardize the process for quality and content.

I hope that the successful implementation of a new, thoughtful program would lower unneeded emergency room visits and hospital readmissions, while increasing the satisfaction and quality of life of ostomy patients. The WOCN Society and the UOAA could be a powerful team to help patients' live full-functioning lives after ostomy surgery, while surpassing their goals for patient care and advocacy. Most importantly, it's a win for the *patient*- and that's what we are all striving for!

Dawnette Meredith: UOAA Board Member - San Diego Affiliate, International Author, Advocate

Citations: * Bridging the Gap (Werth, Sherry; Schuttle, Debra L.; Stommel, Manfred. JWOCN 41(6), p 566-572, 2014),

! Learning to Live with a Permanent Intestinal Ostomy” (Danielson, Ann Kjaergaard; Soeresen, Erik Elgaard; Burcharth, Kristen; Rosenburg. JWOCN, 40(4); p 407-412 2013)

The holiday “Give a Bear Hug” campaign will launch in November 10 and will be available on AwesomeOstomy.com. It's the perfect gift, compassionate, thoughtful gift. Sponsor a bear for a child in someone's name. A beautiful holiday card (2nd photo below) will be sent to them with your personalized message and telling them a bear was sponsored in their name. Each holiday bear hug bear is $20”…

UOAA Discussion Board

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

Medical Care Products, Inc
PO Box 10239
Jacksonville, FL 32247-0239

To: