



**FRIENDS OF  
OSTOMATES  
WORLDWIDE - USA**



## Newsletter Spring, 2022

### President's Message



Dear Friends,

Spring 2022. I feel a sense of hope at this time of year. Hopeful that the grip of the Covid pandemic will be a distant memory very soon. It is such a blessing to begin to meet in person again. I have an Ostomy Support Group Meeting scheduled "in person" for the first time in about 2 years and we are all very excited about gathering together! I am hopeful that we will not take times like this for granted. I have truly missed them.

Technology caused us some issues recently with the FOW-USA website. The team of people who worked on correcting them spent numerous hours and we are happy to report it has been fixed. I want to apologize for any inconvenience it may have caused you and thank you for your patience while we worked through them.

We have been following the invasion of Ukraine by Russia very closely. Many of you have reached out

with offers to help with supplies and financial donations. There are many organizations reaching out to help those affected by this crisis. Some organizations mentioned in current news articles include The Red Cross, Doctors Without Borders, Project C.U.R.E. and there are many others. Our Shipping Coordinator, Ruth Salinger is in close communication with the European Ostomy Association. We have 2 shipments on hold now for groups that we work with in Ukraine. We appreciate your donations of supplies and money to FOW-USA, to support the shipment of supplies to Ukraine and whenever we are able to send them.

We are pleased to have two additions to our volunteer Board in January. Be sure to read more about Ed Merrell & Ryan Golkowski, new Associate Directors for FOW-USA.

Kudos to all our hard-working Board members who continue to support our organization's

mission through the Speaker's Bureau, representation at ostomy related conferences and pursuit of educational efforts for ostomy product recipients.

Sincerely,

*Cindy Barefield*

*"Technology has caused some issues recently with the FOW-USA website...thank you for your patience while we worked through the issues to get it corrected."*

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without our  
Volunteers and  
YOU!**

## Meet our Officers & Board of Directors

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## Shipping Update



**As of May, we have  
shipped 14,688 lbs. of  
products in 2022!**



## Ostomy Pearls :

### Overcoming Physical Challenges with an Ostomy

By Ginger Salvadalena PhD RN CWOCN  
and Charlotte Foley MS OTR/L, CBIS

One of the keys to success in life is to pursue solutions to unexpected events and problems. Adjusting to an ostomy requires learning new skills and integrating these skills into daily routines. Collaboration with specialists such as Wound, Ostomy and Continence Nurses (WOC nurses), Occupational Therapists (OTs), or Physical Therapists (PTs) can help individuals navigate these newfound challenges and produce more successful outcomes.

Adjustments are often needed over time due to health changes and new challenges with age. For example, emptying and applying an ostomy pouching system can be difficult with impaired vision or limited hand function. Measuring the stoma and cutting out an ostomy skin barrier becomes more difficult with reduction in dexterity and hand strength.

Strategies for managing these concerns may include changes in product selection, accessory use, assistive devices, physical strengthening of the body, and integrating a family member or care provider for assistance.

## Ostomy Pearls, cont.



Working with a WOC nurse on simple changes such as using a pre-sized product, a different type of pouch closure, or a closed pouch, may be an option for someone with limited hand function. An accessory product, such as barrier rings or convex products might be suggested to help with fit challenges. For example, a device might be used to help make pouch application easier with visual limitations (stomagienics.com). To get an electronic alert that a pouch is full, it might be helpful to try a wearable technology (11health.com). An abdominal binder might provide protection of the pouch during sleep or when a client is confused and pulls at the pouch. The WOC nurse can share these and other options or techniques to help manage client needs (<https://www.wocn.org/learning-center/patient-resources/find-a-nurse/>).

Occupational and Physical Therapists help their clients become more independent after ostomy surgery by examining the physical, psychosocial, emotional, and cognitive challenges that impact their clients lives and their ability to participate in self-care and mobility related to tasks. They work with their clients to better manage their ostomy despite limitations. Charlotte, an OT based in Anchorage, Alaska described it this way:

*I was working with a patient in the hospital who had his ostomy for a few months. He was an expert at reciting his ostomy care routine and the steps for changing and emptying his appliance. But he was quite deconditioned from a neurological condition that impacted his strength, coordination, and overall mobility. He initially had very few leaks with his ostomy, but as he began to get out of bed and up to his wheelchair more often, he experienced more leaks. So his PT and I (his OT) were asked to monitor for leaks during our sessions to see if we could find the cause. The patient was making progress with his overall mobility and strengthening program with his PT and that did not appear to be impacting his ostomy. But when I was working with him during an OT session, I noticed something that was impacting his routine. The patient had decreased coordination and strength in his hands when he was fatigued, which was making it challenging for him to seal the closure on his pouch and contributing to his leaks. After identifying this problem area, I was able to collaborate with the PT to schedule appliance changes before therapy, I was able to collaborate with the ostomy nurse to find a different style bag that the patient could better manage with the impairments to his hands, and I was able to work with the patient on increasing strength and coordination in his hands. With a team approach to his care, the patient was able to decrease the amount of leaks he was having, was better able to care for his ostomy himself, and was able to discharge home from the hospital with family at a more independent level.*

In summary, change is a part of life. Don't be afraid to talk with your primary healthcare provider for a referral to a



WOC nurse, OT, or PT if self-care skills become difficult. Consider reaching out to a local ostomy support group for ideas as well (<https://www.ostomy.org/support-group-finder/>). It might be time to try something new, change methods and explore options.

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Charlotte Foley has personal experience living with an ostomy and professional experience as an OT. Her business, Restorative Ostomy Solutions, helps empower individuals in their recovery from ostomy surgery. Charlotte's website [www.restorativeostomysolutions.com](http://www.restorativeostomysolutions.com) provides resources for ostomates and healthcare professionals.

## New Board Members

### Edward Merrell

Edward is from Gilroy, California. He works in the seed industry and his educational background is in Biology. Edward also has extensive volunteer experience including his church as the Church Council President. As an ostomate, he is looking forward to applying his professional and volunteer experiences toward the FOW-USA Board of Directors.



### Ryan Golkowski

My name is Ryan and I am an analytical chemist with Crohn's disease. I was diagnosed in 2001 when I was 8 years old. I had my colon removed in 2004 and had an ostomy for 7 years until 2011 when they attempted to reconnect me. The reconstruction ended up causing more harm than good as abscesses and fistulae started to form and branch when I was an undergrad at Purdue. Now that I'm out of grad school, I have been working through the University of Iowa and University of Chicago to get the fistula situation fixed. This last month I had a proctectomy and am currently recovering from that. When I'm not healing from surgeries I am very into fitness and nutrition; I really enjoy to cook and workout. I also am a big gamer, I love to play my Nintendo Switch. I strive to want to be more active in the Crohn's community and be there for kids suffering from Crohn's Disease to assure them that they will get through it and that there is light at the end of the tunnel!



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## We get emails



In 1999 Mustard Seed Communities expanded to Nicaragua to meet the needs of children with mental and physical disabilities, many of whom were abandoned.

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November 2021

Emilio Raul Samudio Balbuena, President  
Paraguay Ostomy Association (ASOSDELPA)

Over the years, FOW-USA has had an impact on the Paraguay Ostomy Association, ASOSDELPA): The President writes, "We are a group of volunteers, we serve two groups a month. We are almost 500 ostomized currently."



## We Get Emails, cont.

### Morocco 2022

Hello -

We are so grateful for the donation of ostomy supplies that we received from « Friends of ostomates worldwide » ....

Your gift helps us to support more people like BATOUL (in attached picture) to live a happy and healthy life. We couldn't do it without you. Together we are changing lives.

From all of us thank you so much for your generosity.  
Asmae



Mexico, April 2022

Hope everything goes well. I want to confirm receipt of my shipment last March 17.

Everything was received correctly packed and according to the list that you attached to me.

I am eternally grateful with FOW - USA, for the support and the speed with which my request was dealt with.

Best regards, Salvador



We will be attending the WOCNext Conference in June in a virtual booth. Be sure to log in and say "hi" and chat with a board member. We are raffling off a special gift for attending!

## We Get Emails, cont.



April 2022 Dominican Republic

Hope you are well. This is a appreciation email, I on behalf of Ostomizados RD, [Dominican Republic] just wanted to thank you for all your help and dedication to ostomized patients all over the world.

These are babies that we have been able to help for the last couple of months thank to your generous donations, without FOW USA some of them would still be using plastic bag taped to their skin. They are all under 5 years old ...

Regards,  
Dr. Ramona Lappot, Ostomizados RD

2022 Cuba via Florida

A man in Florida asked us to send him supplies, so that he could mail them to his grandmother in Cuba. He requested several different sizes and equipment types. When we asked what she preferred, he said "... it may seem strange to you that you can use various types of bags, but sometimes due to the scarcity of these products in Cuba, my grandmother has had to use a supermarket bag, thank you for everything you do and all the work team." Your financial and product donations allow individuals to live with dignity and ease.

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The Mission of Friends of Ostomates Worldwide-USA (FOW-USA), a volunteer-run, non-profit organization, is to provide ostomy supplies and educational resources at no cost to ostomates in need around the world.

FOW-USA  
4018 Bishop Lane  
Louisville, KY 40218  
USA  
Tel: 502-909-6669

Address Service  
Requested



### Friends of Ostomates Worldwide—USA Contribution Form

Name \_\_\_\_\_

#### *Giving Level*

Address \_\_\_\_\_

Partner-\$50\_\_\_\_\_ Corporate-\$300\_\_\_\_\_

City State Zip \_\_\_\_\_

Sustaining-\$75\_\_\_\_\_ Benefactor-\$1,000\_\_\_\_\_

Country \_\_\_\_\_

Contributing-\$150\_\_\_\_\_ Lifetime/Memorial-\$5,000\_\_\_\_\_

Telephone (\_\_\_\_) \_\_\_\_\_

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E-mail Address \_\_\_\_\_

Chapter/Group/Association \$ \_\_\_\_\_

Send Newsletter by E-Mail? Yes \_\_\_\_\_ No \_\_\_\_\_

**Total Amount Enclosed - \$** \_\_\_\_\_

**Make checks payable to FOW-USA and mail with form to:**

**FOW-USA, Attn: Treasurer, 4018 Bishop Lane, Louisville KY 40218-4539**

**If your employer has a matching contributions program, please ask them to match your gift.**

**To Donate On-Line: Go to [www.fowusa.org](http://www.fowusa.org) and click on Donate.**