

***“Despite these adverse conditions, the FOW-USA organization has remained resilient.”***

### Inside this issue:

Meet Our Officers & Board of Directors, Ostomy Pearls	2
Ostomy Pearls cont, Pandemic Challenges & Opportunity	3
On the Road Again & 2021 Service Award Recipient	4
Meet Our New Board Members	5
We Get Emails & Annual Board Meeting	6
We Get Emails, cont.	7
Donation Form	8

email us at  
[info@fowusa.org](mailto:info@fowusa.org)



## Newsletter Fall, 2021

### President's Message

Dear Friends,

Coronavirus – Pandemic - Social Distancing - Vaccination – topics we rarely spoke of are now “front page news” to people around the world since the outbreak of the Coronavirus in January 2020. Despite these adverse conditions, the FOW-USA organization has remained resilient. In response to ostomy support groups that began meeting virtually, FOW-USA volunteers adapted the original PowerPoint presentation to a speaker's bureau to engage with these groups virtually. Read more about this project in Shelly Miller's article in this newsletter.

Flexibility is another key component in resilience. Our website undergoes monthly review.

Realizing that donations of ostomy products are crucial to the FOW-USA mission, an update, “Follow the Shipment” was added to the donation process. The SpokesPouch caricature is used to illustrate the donation process in less than a minute. To facilitate financial donations online, an

additional upgrade to the Donations tab allows for credit card donations. In addition, automatic monthly recurring donations are now available for the first time in our organization's history.

FOW-USA volunteers support each other – another important resilience factor. With several of our nurses working “the front lines” during this pandemic, their ability to continue to serve the Board was difficult. With communication and collaboration, duties were able to be shared or re-assigned, and the work continues!

Despite adversity created by volatile interactions between countries, government office closures, escalating shipping costs, and landlocked recipients, our shipping coordinator and warehouse volunteers adapted to changes and continued to send out supplies. Public Relations volunteers provide support with eblasts, Facebook and Instagram

posts that update our viewers on current needs.

Appreciation goes to all of these FOW-USA volunteers who make our mission to provide ostomy supplies and educational resources at no cost to ostomates in need around the world a reality.

Sincerely,

*Cindy Barefield*



facebook

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We can't do it  
without our  
Volunteers and  
YOU!

## Meet our Officers & Board of Directors

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Shelly Miller Rancho Mirage, CA

### Treasurer

Mickey Heideman Prospect, KY

### Warehouse Manager

Carol Heideman Prospect, KY

### Immediate Past President

Ann Favreau Venice, FL

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Shelly Miller Rancho Mirage, CA

Ruth Salinger Bethesda, MD

Ginger Salvadalena Tulalip, WA

Maja Ingeman Minneapolis, MN

### Facebook Administrator

Heather Martinek Marlton, NJ

### Google Administrator

Nancy Schuller Brookfield, IL

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Jan Colwell

Craig Glazer

Rachel Hendee

Dorothy Kent

Lynne Kramer

Wendy Kunz

Ashley Mann

Ruth Salinger

Ginger Salvadalena

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Chicago, IL

Falls Church, VA

Chicago, IL

Lower Gwynedd, PA

Philadelphia, PA

West Deptford, NJ

Fayetteville, NC

Bethesda, MD

Tulalip, WA

### Industry Advisors

Rachel Kaminski

Maja Ingeman

Heather Budorick



## Shipping Update



We recently sent our  
first shipment to  
Qatar, and we now have  
shipped to 98 countries!



## Ostomy Pearls

Zoe Bishop RN, BSN, CWOCN

In my job, I advise patients before and after ostomy surgery to help prepare them for this change in their body.



When talking to my patients before and after their surgeries, I often clarify information they have heard from their next door neighbor or the parishioner that sits beside them in church. One detail for example, is if you are going to be an ostomate with a diversion on your abdomen that releases stool, it should not have any effect on your urinary system. It is amazing the sign of relief on some of their faces! They may have also been misinformed. "I heard that they leak at least once a day; what do I do then?" I share information about customizing product fit and the help an ostomy nurse provides. Many ostomates have very good wear times and seals with their wafers, so can be assured that they can get back to their usual routines.

It is always good to point out resources that are available after a patient leaves the health care setting. They should develop a relationship with their WOC nurse and the clinic where they can make an appointment for any issues that they have.

## Ostomy Pearls cont.

Their surgeon may be able to help them, and they would always need to know how to contact them for other issues that may arise as well. They also can use the manufacturer's 1-800 number to talk with a clinician that may be able to offer suggestions over the phone. Manufacturers will often send a sample or two if they recommend a different pouch.

Another resource is a support group...yes, a support group, where people can talk with and share some of their anxieties with other people who also wear a pouch! New ostomy patients need to know where their resources are, and how to contact them before they leave the hospital.

And lastly, "where do I pick up these bags?" is a common question. There is not a store in the mall. Can they buy them from Amazon? The answer is yes they can, but it would be an expense straight from the billfold with no reimbursement. I give them a list of product distributors and coordinating insurance benefits before they leave the hospital. The patient should have a schedule that the WOC nurse suggests and works out with the patient on the best schedule of changing the pouching system that will make good use of the number of pouches they can receive in a month. As clinicians, we never know everything and have learned a lot of what we do know from the patients we care for. Making them feel ready to manage their ostomies themselves is a challenge, but each day at a time is an important way to look at the effective management.

FOW-USA is always thankful for individuals and groups who donate their extra ostomy supplies. It is a gift to these patients to get supplies, and a gift to those less fortunate to have that box delivered to their door. Remember that when you have extra pouches, DO NOT throw them away. Send them to FOW-USA in Louisville so we can connect with those less fortunate with your gift. I can assure you, the availability of ostomy products changes lives.

### PANDEMIC CHALLENGES AND OPPORTUNITIES

**Shelly Miller FOW-USA Secretary; PR Committee Chair**

FOW-USA was not spared the angst so many experienced since March 2020 when Covid-19 changed the world. We were faced with shipping hardships as many countries would not allow any goods to be shipped in. We had to restructure our warehouse volunteer schedule. Supplies to re-ship to needy ostomates came in at a slower rate and like most other organizations that meet in person, we were forced to meet via Web-based, virtual meetings.

The good that came from the latter was that Board member, Dorothy Kent, had a wonderful brainstorm. Since many UOAA Affiliated Support Groups (ASGs) were also forced to meet virtually as well, why not offer to join their meetings and tell the FOW-USA story. Having an FOW-USA "expert" as the guest speaker would be a unique approach to filling the needs of their groups for speakers and allow FOW-USA to show how we are making a difference in the ostomy world. The idea was circulated around our board, and several Directors volunteered to join our new "Speakers Bureau".

Once we had our list of speakers, we held a roundtable brainstorming session to outline our presentation for consistency. Then Dorothy reached out to over 100 ASGs offering our service to guest speak at a future meeting. In the past, we always offered to attend live ASG meetings in cities and towns close to where our Directors live, but this concept would open our ability to make presentations in more remote locations or big cities where we did not have anyone close enough to attend. It has been very successful and the volunteers rotate as able to attend these meetings and spread the word about the FOW-USA mission. We each use the PowerPoint, take attendees on a tour of our website, discuss the need for both types of donations (supplies and financial) and lend some tips on shipping supplies to us in Kentucky that saves the sender shipping costs. If you attend an ASG or run one and would like an FOW-USA Director to join a future meeting, email us at [info@fowusa.org](mailto:info@fowusa.org) with your request and be sure to include the dates of your future meetings from which we can choose. We hope you will take advantage of this terrific opportunity.



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## On The Road Again

The words from the song “On The Road Again” can be used figuratively and literally. In this case I’m referring to the latter. The next two lines of the song are also appropriate. “Like a band of gypsies we go down the highway. We’re the best of friends.” Danielle Gulden and Joe Teeters are comedians, speakers, and advocates. Each of them has an ileostomy as well, and together, Danielle and Joe go by the name “Double Baggin’ It”. In August they made their annual 8-hour round-trip car ride to our Louisville, KY, warehouse to deliver ostomy supplies.

Danielle and Joe are volunteers and officers with the Central Ohio United Ostomy Association (UOA). This support group has a “closet” where they accept donations from local ostomates and caregivers. These supplies are then available to those in need and who may have little or no insurance. Once it has been determined that they have enough supplies on hand for anyone in the central Ohio region who may need assistance, they pack up the rest and take their annual road trip to our warehouse in Louisville, KY. They encourage other support groups to do the same. We want to thank Danielle, Joe and the Central Ohio United Ostomy Association for all of their product donations. We are fortunate to partner with our donors and eagerly await their next ostomy road trip.

If you want to read more about Danielle and Joe’s escapades you can find them at <https://www.doublebaggin.it.com>, Facebook, Instagram, Tiktok, Twitter, and YouTube using the handle: @DoubleBagginIt.

If you would like to take a road trip to our warehouse, please contact our Warehouse Manager, Carol Heideman, at [warehousemanager@fowusa.org](mailto:warehousemanager@fowusa.org) or call and leave a message on our phone line at 502-909-6669.

## Dorothy Kent



## 2021 FOW-USA Service Award



Richard Murahata has been a supporter of the FOW-USA mission for over 20 years, offering wise, measured counsel, and researching issues that have come up during Board meetings. From 2010-2013 he served as an Industry Advisor representing Hollister Inc. When he retired in 2014, he joined the Board and has been an active member until 2021. Richard served on the finance committee and attended conference calls, Zoom and the annual meetings in Louisville where he brought a level of knowledge and professionalism that has been unmatched. He has been consistently steady and reliable in his contributions, always following through on commitments. His knowledge is so broad that, in addition to the world of ostomies, his knowledge in the finance and fundraising side gained us major insights and ideas.

In appreciation for a long and respected career with FOW-USA, we are proud to designate Richard Murahata, our friend and colleague, the winner of the FOW-USA Service Award for 2021. Richard received a certificate of achievement and a token gift of our appreciation.

## Meet Our New Board Members



For over 30 years **Ginger Salvadalena** practiced Wound, Ostomy and Continence Nursing, first as a Medical Surgical Clinical Nurse Specialist in acute care hospital practice, and since 2002 in various roles in the medical device industry. Dr. Salvadalena earned her Master's Degree at the University of Washington in Seattle, Washington and her PhD in Nursing at the University of Illinois at Chicago, Illinois.

She is a certified Wound, Ostomy and Continence Nurse. Her research interests include stoma and peristomal complications, stoma site marking, and stoma management. Ginger has authored multiple peer-reviewed publications and book chapters, and presented to national and international audiences. Ginger served as an Industry Advisor to FOW-USA until May of 2021 when she retired from Hollister Incorporated.

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**Ashley Mann** is a 28-year-old living in North Carolina with her husband of 7 years, Travis Mann. Ashley was diagnosed with Crohn's Disease at the age of 20 and quickly found herself needing a temporary ileostomy before choosing to make it permanent in 2016 as her disease progressed.

Since then, she has become involved with multiple organizations by volunteering at events, speaking at colleges educating future nurses, leading support groups, volunteering as a camp counselor, and representing ostomates as a patient advocate.

Taking a more active role with Friends of Ostomates Worldwide – USA, Ashley hopes to continue this pattern of positivity while expanding her reach and furthering the goals of an organization she has been invested in for years.

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**Lynne Kramer** is a retired math teacher with 35 years of experience spent mostly in the Philadelphia School System.

Lynn had ileostomy surgery in 1977, followed by a Koch Pouch in 1990. In 2018, after some issues requiring surgery, her pouch was revised back to a Brooke Ileostomy.

Lynn has been a member of both the UOA and UOAA Board of Directors, as well as the Treasurer of the Philadelphia Support Group for many years. She is also a certified visitor, and she helped to plan and present Visitor Training programs for the Philadelphia group.

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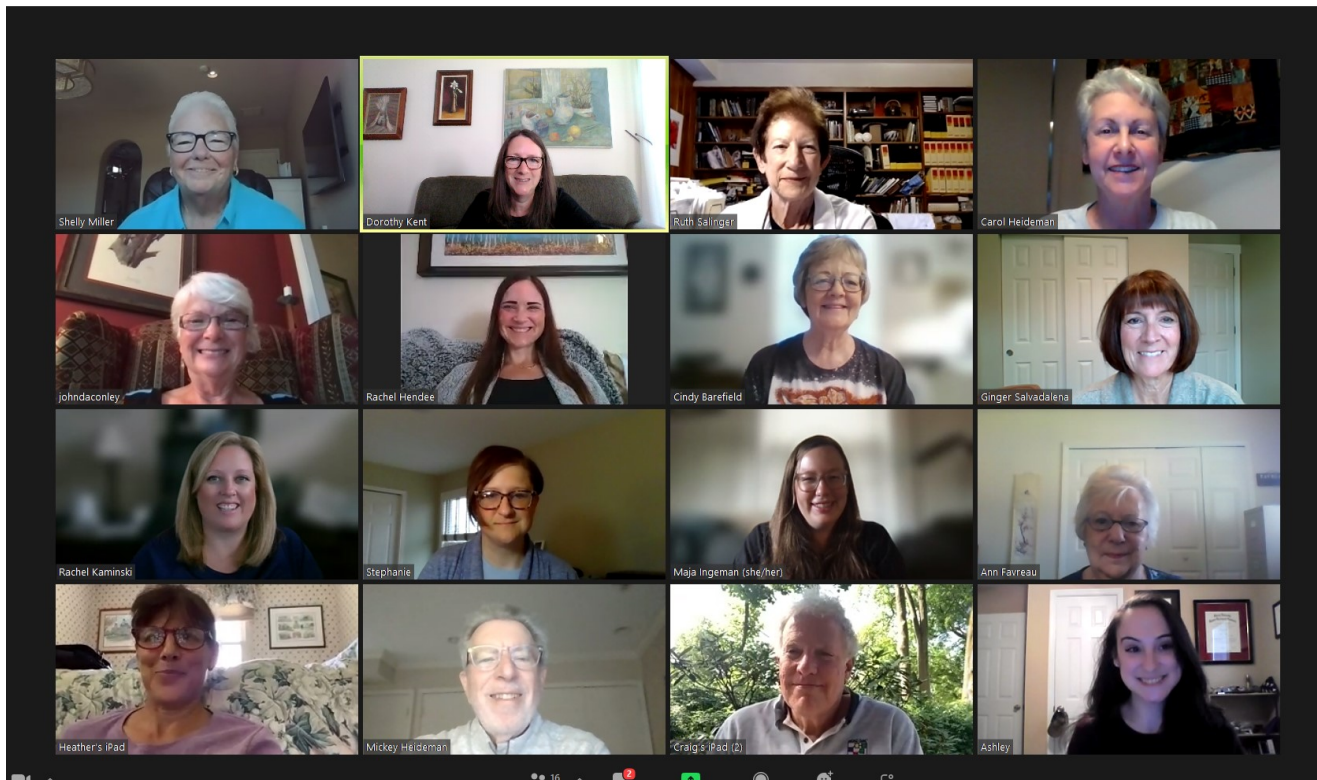
## Help Us Help Others!

Every few years we find ourselves with a few new openings for additional volunteers. So many of our Directors are in it for the long haul, and we could not achieve our mission without all of these unselfish people who roll up their sleeves for the good cause.

On occasion, we open additional positions and like to "build our bench". Sometimes a Director retires or moves on to another mission. Our Directors and volunteers come from all walks of life and from all over the United States. We have a few folks who live close to our warehouse in Louisville, Kentucky who receive, unpack, sort, stage, repack and ship the supplies to those in need.

Our Board of Directors consists of ostomates, friends and spouses of ostomates, WOC Nurses and those in the industry, Finance wizards and the like. Because we are a 100% volunteer run group, our need for skills in marketing, social media, fundraising, transportation, database management, and computer skills are never ending and "new blood" is always welcomed. Do you have a few hours a week to contribute your talent from the comfort of your home and be a part of this amazing organization? Want more information? Just drop us an email at [info@fowusa.org](mailto:info@fowusa.org) and someone will get back to you. You can be part of our amazing team and help us make a difference in the lives of needy ostomates around the world.

## 2021 Annual Board Meeting



(Board members not pictured: Jan Colwell, Lynne Kramer, Wendy Kunz)

Covid-19 wasn't going to stop us from our annual meeting, held October 3, 2021. This year's meeting was virtual and we hope to conduct our 2022 meeting in person, in Louisville, KY.

## We Get Emails



August, 2021 Guatemala  
Ana Sherrill and Hector Manuel, her father

Just wanted to say thank you for all the supplies that were sent to my dad. He will be 90 next month and [a] colon cancer survivor for 11 years, currently suffering from diabetes and having kidney problems but receiving all these supplies made him smile because [it] is one less worry for him. We are so blessed for your help as you know other countries do not have all the medications and supplies needed neither do they have the money to afford it or insurance to cover ... I found him in good spirits and he says just one day at a time ...



## We Get Emails cont.

November, 2020

Tarek El-Shayal, Chief Operating Officer of the Global Healthcare Education Initiative (GHEI) Uganda, traveled to the Bugando Hospital in the Northern Tanzania Lake Region. He joined Lameck Otero, Managing Director, Nyanza Kenya Ostomy Association, to attend 2 colo-rectal clinics. Stoma bags were given out to all parents and Mr. Lameck taught them how to install and use them. We appreciate all of their hard work in using our donated supplies to help families in need.



August, 2021

Dr. Ramona Lappot, Ostomy Group of Dominican Republic

Hope you are well. This is an appreciation email. I, on behalf of Ostomizados RD, 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 thanks to your generous donations, without FOW-USA some of them would still be using plastic bags taped to their skin. They are all under 5 years old and their diagnosis are imperforate anus, colonic atresia and congenital aganglionic megacolon.

Regards,  
Dr. Ramona Lappot, Ostomizados RD

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The advertisement features a black and white photograph of a person in a dynamic pose, leaning forward as if riding a bicycle or running. In the foreground, a hand is shown holding a white, circular ConvaTec skin barrier. The background is a simple, light-colored wall.



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

Supporting-\$300\_\_\_\_\_ Other-\$\_\_\_\_\_

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

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

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

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

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**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.**