



## ***Friends of Ostomates Worldwide-USA***

***The Mission of Friends of Ostomates Worldwide-USA (FOW-USA), a nonprofit volunteer run organization, is to provide ostomy supplies and educational materials to help ostomates in need around the world.***

### **2<sup>nd</sup> Annual Fundraiser**

By Shelly Miller

As we went to press with the Fall 2014 Newsletter, we reported on the initial indicators that the October, 26, 2014, 2<sup>nd</sup> Annual FOW-USA Fundraiser held at The Painted Penguin in Aurora, Illinois was a success. That was an understatement! Once all of the numbers were tallied and donations and expenses calculated, the event netted in excess of **\$11,000!** This FAR exceeded the expectations of Fundraiser Task Force Chair and organizer, Robin Nasatir.



*Pictured: Task Force Committee l-r: Nancy, Marilyn, Robin, Jan, Herb, Shelly*

Robin's vision of holding this annual event and donating space at The Painted Penguin as well as providing Topper their mascot, numerous prizes and her generosity goes beyond words. The event was attended and supported by GI Doctors, WOCN nurses, ostomy support groups, medical suppliers, ostomy product manufacturers, ostomates, friends and family.



Donation & Supporter Thank You Board

Over 40 attendees participated in painting activities, a silent auction, 50/50 raffle, and more. Eighty-five items or baskets were raffled including tickets to major Chicago team sporting events, jewelry, artwork, and so much more. Refreshments were enjoyed by all.

FOW-USA would like to thank EVERYONE who supported this event and look forward to an even more successful Fundraiser in 2015.



Artists in action!

### ***Newsletter Spring 2015***

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**Send Supplies**

**and Contributions to:**

**FOW-USA**

**4018 Bishop Lane**

**Louisville, KY**

**40218**

**Tel: 502-909-6669**

**E-mail:**

**[info@fowusa.org](mailto:info@fowusa.org)**

**Website:**

**[www.fowusa.org](http://www.fowusa.org)**



facebook

## Officers and Directors

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Janice Colwell Chicago, IL

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Ann Favreau Venice, FL

### Secretary

Nancy Schuller Brookfield, IL

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Mickey Heideman Louisville, KY

### Warehouse Coordinator

Carol Heideman Louisville, KY

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Ival Secrest Sierra Vista, AZ

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Patrick Greco	Louisville, KY
Al Maslov	Wilmette, IL
Heather Martinek	Marlton, NJ
Shelly Miller	Palatine, IL
Richard Murahata	Denver, CO
Ruth Salinger	Bethesda, MD

### Industry Advisors

Punnie Donohue



Sonia McDonough



Ginger Salvadalena



### Newsletter Editors

Shelly Miller

Palatine, IL

Walt DeMoss

Oswego, IL

## Do You Shop Amazon?

FOW-USA is now registered as an Amazon Smile Charity. FOW-USA receives one half of 1% on approved purchases that you make when shopping on their site.

1. Login at [www.smile.amazon.com](http://www.smile.amazon.com)
  2. On the right hand side of the site you pick your charity.
  3. Enter FOW-USA
- This will now be added to your profile

Thank You!

## President's Message

Dear Friends,

Friends of Ostomates Worldwide—USA has undergone a growth period over the last few years. We have examined our mechanisms for communication and worked to improve them to help communicate our mission.

Our newsletter has been revamped by our newsletter editor Shelly Miller to provide information on FOW-USA activities. Our Public Relations Committee headed by Ann Favreau has worked on developing print ads and articles to the ostomy community as well as helped us to organize our attendance at ostomy related meetings. Ruth Salinger continues to work with our volunteer webmaster to keep our website ([fowusa.org](http://fowusa.org)) up to date as this is our main communication tool to many in need of ostomy supplies. Heather Martinek works as our Facebook volunteer getting the word out about our work on social media.

As I travel around the country participating in lectures to ostomy health care providers, I am sure to talk about FOW-USA to increase awareness. Our efforts have paid off as we see more product donations as well as an increase in financial donations; but we are still in need of both.

To continue to meet the need of people around the world who are without products to manage their ostomies, we need the following: **Product donations:** pouches, flanges and accessory items. We have a huge need for pouches & flanges that are 2 1/4" or larger. When you are sending products, keep in mind that you can remove the products from the boxes to lessen the size and weight of the products that you send. Tear off the Manufacturer's box top with the info and drop that into a plastic baggie with the supplies. At the warehouse we can sort the products into bins that we have with each product size and type.

**Financial donations:** we use our financial donations to pay for shipping around the world and for the running of our warehouse (rent, utilities). Our entire staff (board members as well as warehouse volunteers) is not paid; we all volunteer our time and energies.

**A Database Manager:** we have a database that we use for our product and financial donors, to send acknowledgements and to distribute our newsletters and appeal letters. Our database manager recently left the board and while she is graciously supporting the database, we need to find a volunteer to take over this function. If you know of someone with these skills (you or someone else), please contact me at [info@fowusa.org](mailto:info@fowusa.org). This is such an important function for us, and we need your help in finding a new database manager.

## FOW-USA Mourns the Loss of Director, Marilyn Zuckerman

On February 12th, 2015, we received the sad news of the passing of FOW-USA Board member Marilyn Zuckerman.

Marilyn became a member of the Board in the 1990's and she shared her wisdom, knowledge and loyalty to the cause throughout the subsequent years. She served FOW-USA in various roles including Board President, working tirelessly on so many important projects. Marilyn recruited new members, raised funds and provided inspiration to the rest of us about the importance of the FOW-USA mission. For many years she was editor of this Newsletter, served on the fund raising committee as well as numerous task forces. It will be hard to imagine our board without her.

A tribute to her life was held near her home in Wisconsin on April 11, 2015. Her family generously requested that any memorial contributions made in her name be made to FOW-USA. Our condolences go out to her husband Alan, her children, grandchildren and the rest of her family.

FOW-USA Board of Directors



### FOW-USA Scholarship Donation

By Ruth Salinger

One of the missions of FOW-USA is to support education for ostomy health care providers in developing countries. We recently donated funds to the World Council of Enterostomal Therapists (WCET), specifically to their Norma N. Gill Foundation (NNGF). Norma Gill was the world's first Enterostomal Therapist and founder and first president of the WCET. The fund named in her honor raises money for nursing scholarships for ET education.

The NNGF Chairperson, Carmen George, wrote in her thank-you to us: "I have been informed that the generous and kind donation from [Friends of Ostomates World – USA] has arrived in the NNGF account. This amount is enough to fund 26 membership scholarships.

Membership scholarships are really valued by people who have an interest in stoma, wound and continence nursing in countries where they don't have the disposable income to afford this .... In the next copy of our WCET journal in the honours list this generous donation will be acknowledged. Please can you pass on the sincere thanks of the WCET board."

### ATTENTION OSTOMY PRODUCT USERS!

Do you...

- ✓ Have opinions?
- ✓ Have access to a computer?
- ✓ Care for your own stoma?

If YES, you qualify for the  
**OSTOMY RESEARCH PANEL**

Panelists are compensated for participation in research studies

For more information contact  
**[researchostomy@gmail.com](mailto:researchostomy@gmail.com)**

Products or services advertised in this Newsletter do not represent an endorsement by FOW-USA



## Ostomy Pearls

### Changes in the Weight of an Ostomate

By Nancy Schuller

One of the questions that a medical clinician will usually ask an ostomate who is having a new problem with obtaining a secure seal or shortened wear time is: Have you gained or lost any amount of weight? Why is the answer so important?

While weight gain or loss may be desirable based on your medical status, it is important to remember that it may affect your pouching system. Weight gain or loss can change the shape of the abdomen. In both gains and losses, a person's ostomy pouching system may no longer be able to consistently adhere to the skin. With a gain in weight, the belly's contour can become rounder, firmer, and/or softer. The rounder and firmer abdomen can result in a pulling of the adhesive and not conforming to the abdomen's shape. Loss of weight can make the skin around the stoma to become looser, flexible, and with creases. As a result, the pouching system may not be flexible enough to move with the skin or mold into the creases.

In addition to the changes in the abdominal skin contour, the stoma itself may be affected. Weight gain may cause the stoma height above the skin to become shorter. Where once the stool or urine went up and into the pouch, the waste now may be pooling around the stoma. Also, the stoma that was once easily visible may now be located toward the underside of the abdomen or off to the side of the curve of the abdomen (Figure 1). It no longer sits on the flat portion of the belly. Conversely, weight loss would make the stoma above the skin longer. The opening in the stoma can be affected, too. The hole that was once right in the middle, can now be puller on an angle; upward, sideways, or downward.

While changes in a person's weight may not be the reason that a pouching system is no longer working properly, it is one avenue that needs to be considered. Fortunately there are pouching systems available that can be helpful.



Figure 1

## Gener—Ostomy

By Shelly Miller

Two stories of generosity of the utmost level have recently surfaced with FOW-USA being the benefactor.

The first comes from Detroit, MI, home of Ariana Abel. On January 10, 2015, Ariana held a celebration of life and her 50th birthday with dinner, drinks and dancing. In her post-dinner speech, she explained how Crohn's disease almost killed her but having gone through a colectomy, she was "just fine". She went on to thank those present for their prayers, flowers, phone calls, visits, transportation, and generosity in giving of themselves. She continued to say, "I am blessed to have a job that affords me good medical insurance. I MUST have ostomy bags and they are NOT cheap. If I were to lose my insurance I don't know what I would do to get my supplies."

"Then one day I heard of someone who was in that exact predicament, and was desperate. I've also read about people in underdeveloped countries who fashion plastic bags or towels to their stomach using tape or tying a scarf around their waist. They are shunned and ostracized by others, including their own families, because they are dirty and smelly. My heart goes out to those who can not get ostomy supplies. There is an organization, run by volunteers, that collects supplies and sends them to those in need."

Her very moving speech culminated in her birthday wish.

"That we donate to the Friends of Ostomates Worldwide [USA]. You've all been there for me already. Let us now be there for others not as lucky as I have been. Thank you so much. I love you."



Ariana Abel, Guest of Honor

To date, FOW-USA has received **\$1,285** in honor of Ariana's 50th. Ariana, thank YOU so much...we love YOU!



As ostomates in the United States we have learned that throughout the world, ostomates are not as fortunate as we are in regard to securing products and accessories.

One gentleman had supported FOW-USA's work overseas for over 20 years and at his death included a sizable donation to FOW-USA in his will.

What an easy way to perpetuate your passion for helping others by leaving a legacy of funds to FOW-USA. We gratefully acknowledge this exceptional donation.

## We Get E-Mails

March 11, 2015

Dear FOW,

I was overwhelmed at what was received! This lot would help many people here. Thanx again. Personally I thank you as some of the items had come just in time for me - had ran out of Stoma Powder, Paste, Barrier rings. Now got them all.

You know, I had changed bags 300 times so far; the 301st time with the bag from your lot! I was managing with one belt for over 2 years; now got an extra belt.

Bless your heart!

David, Ostomy Supplies & Service Support Group, India

October 21, 2014

Dr. Brian Camazine founded the non-profit group, Earthwide Surgical Foundation, with the goal of delivering surgical care to the poor of the world by means of manpower, equipment and education.

Dr. Camazine writes: "My next trip to Nigeria is coming up on November 2. The patients are lined up for miles. Fortunately, Nigeria is now considered Ebola free." Friends of Ostomates Worldwide-USA (FOW-USA) has donated ostomy supplies for patients there.

Dr. Camazine thanks us in his 2014 report, saying, "this is very important for these unfortunate patients since quality ostomy supplies are either not available or very expensive in Nigeria."  
{FOW-USA sent supplies for his next trip.]

January 26, 2015

Anonymous From Ethiopia:

I received the package you sent to me with big appreciation. I am very much happy to take it. I got it at the right moment. I was really in need of it. I think I can go to work now using the help of the materials you sent.



January 22, 2015

Dear Ruth;

this was and still great good news from us here in Zimbabwe, to receive this supply, May God bless you and your Org for anything you do for us and anyone in need.

Mr. J Muchesa  
Managing Director  
Ostomates Zimbabwe Support Trust  
Hillside | Harare | Zimbabwe

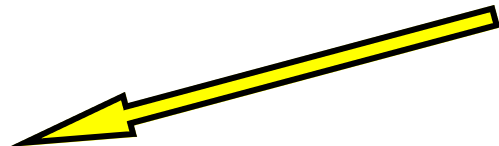


*Pictured: Ostomates Zimbabwe Support Trust opening shipment*

August 13, 2014

I thank you very much for your assistance. we have received ostomy bags and accessories. thanks for all friends of ostomates staffs and others voluntary and sportive staffs; without your and their devotion to help the need; how life would be a [big] mountain that is hard to climb.

Solomon Tsige  
Ethiopia



February 24, 2015

From a meeting of one of our recipients, the B P K Memorial Cancer Hospital, in Nepal. Note the group's theme: Team effort for dignified living.

Thank you  
Dr. Nirmal Lamichhane.

## President's Message cont'd

*Continued from p. 2*

**A Volunteer Fund Raiser:** we have recently lost our fundraiser Marilyn Zuckerman (see article on pg. 3). Marilyn led the charge for fundraising for FOW-USA and was very effective at it! We have a fundraising committee that worked with Marilyn and we are now in need of a leader of that committee. For more information on the committee chair position contact me at [info@fowusa.org](mailto:info@fowusa.org).

Our growth has also set the ball in motion to expand our Board of Directors beyond our current numbers. Please see the request for interested volunteers in the article to the right.

Thank you for your continued interest in the work we do at FOW-USA. Really it's the work YOU do because you have supported us in many ways and we ask that you continue to do so.

*Jan*

## Philippines Sea Dwellers

By Ruth Salinger

We received a request for ostomy supplies from Dan Johanson, US director of Badjao Bridge. The group works with sea dwellers in the Philippines, the Badjao people (<http://www.badjao.org/>). They struggle to maintain their fishing livelihood, which they have engaged in for over 1500 years. Moreover, children face health issues, lack education, and have to beg in cities to avoid family starvation.

After we sent supplies, we received information about the recipients from Wilfreda ("Weng") Amper, who works with Dan. In addition to using the supplies herself (her first donation since 2008), she wrote us about others she provided supplies to.

Here are summaries of their stories:

After his surgery, a pastor could not work, and was not able to get bags or they were too expensive. He improvised his bags by using a coffee cap with pasted plastic and tied it around his body; odor was an issue. "Since the income of his wife is not enough for the family [it's] really impossible for him to buy beautiful colostomy bags like the ones that you gave."

Another recipient is married with 4 children. Her work as a nurse does not provide enough income; she struggles on where and when to buy colostomy bags. She and her family were very grateful for the donation.

Weng also will bring urostomy supplies to the former surgeon who performed surgery on her for free. He is located on another island.

From Weng, "now that we have bags, we now [are] free from worries, insecurities, and fears. Thank you for sending us bags for our daily use." Their photos can be found on our Facebook page.

## FOW-USA Seeking Board Members

### Do You Want to Help Needy Ostomates Around the World?

The Friends of Ostomates Worldwide-USA is a volunteer-run, non-profit organization, providing ostomy supplies and educational materials to ostomates in need around the world. Founded in 1968, we collect donated ostomy equipment from individuals and groups in the US, and send overseas, through clinics, hospitals, cancer societies, and ostomy groups. Please see our website: [www.fowusa.org](http://www.fowusa.org)

Imagine not having the equipment we are used to, because of cost or availability, and using rags, plastic bags, and tape. Imagine having skin breakdown and odor. Your family and community may reject you, and your kids may not be able to go to school.

We have been making a difference for needy ostomates, sending over 300,000 pounds of supplies, worth over \$15,000,000, to over 70 countries.

We are looking for a few volunteers for our Board of Directors. We meet by teleconference several times a year as necessary. We have one face-to-face meeting a year. We need those committed to the ostomy cause; with access to a computer; and willing to serve on a task force or committee matched to your skills (e.g., public relations; fund-raising; databases; web-site).

Please go to our website and click on [contact us](#) to express your interest. We will need a reference regarding your previous or current volunteer work.

## 2015 FOW-USA Board Meeting

The 2015 Annual Board of Directors Meeting has been slated for Saturday, September 5, 2015 in St. Louis, MO, in conjunction with the UOAA conference.

We typically meet face to face once a year to work through our agenda. All other meetings throughout the year take place via conference calls. During years when there is no UOAA Conference, we meet in Louisville, KY, home of the FOW-USA warehouse, where we get the opportunity to thank (and assist) our amazing volunteers.

Agenda items at the time of this writing are budget review, database update, reports from all committees, update of 2015 Fundraising Event, elections and other normal business.



## Visit our booth at these upcoming Meetings:



FOW-USA Director Ruth Salinger

June 7-9, 2015  
WOCN National Conference  
San Antonio, TX

September 3 & 4, 2015  
UOAA National Conference  
St. Louis, MO

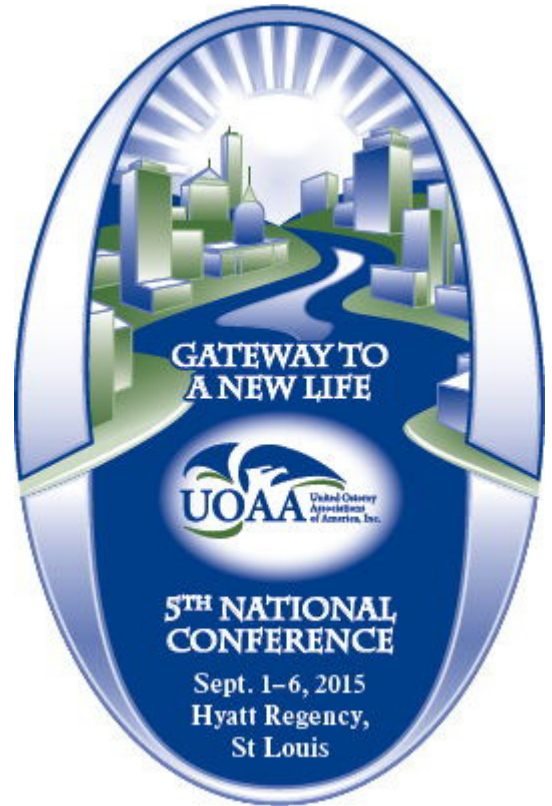
## Mark Your Calendar:

October 3, 2015  
National Ostomy Day



### HELP!!!

**FOW-USA is currently receiving requests for more items than we have available to ship. FLANGES & POUCHES IN ALL SIZES ARE NEEDED, except for 1 and 3/4 inch flange. We are particularly short of 2-1/4 inch Pouches & Flanges & pediatric supplies.**



Visit our Booth at the Expo  
in St. Louis  
September 3rd & 4th!

## 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 - \$ \_\_\_\_\_**

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

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

**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 Donations.**

**FOW-USA  
4018 Bishop Lane  
Louisville, KY 40218  
USA**

**Address Service Requested**

**Spring 2015 Newsletter**

