



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.

We Get E-Mails

2/27/14

Dear FOW-USA:

We are a group of Presbyterians from a collection of churches stretching from south Jersey to Baltimore. Our particular group is centered in four congregations in Delaware and eastern Maryland.

We work mainly in the center of the island, el Centro Presbytery [Cuba], a place where doctors and nurses are plentiful but supplies and equipment can be sketchy. We generally carry, in addition to the colostomy bags I carry, about 100 -150 lbs. of OTC (over the counter medicines). When the residents see



Pictured: John Potter and supply recipient

300th Shipment!

On March 24th, we sent our 300th shipment of ostomy supplies to needy ostomates overseas, since our warehouse moved to Louisville, KY, in May 2008.

Thanks to all of our financial and product donors and to our hard-working volunteers, past and present. So far this year we have made 53 shipments to 31 countries of just under 10,000 lbs. of supplies. That makes our 549th shipment since our first shipment in 1989. For our shipping history, please go to our general website: www.fowusa.org.

None of these could happen without YOU!

Follow us on:



twitter

tall norteamericanos walking in town, they know that there are meds at the Church and arrive looking for NSAIDs (non-steroidal anti-inflammatory drugs), antibacterial or antifungal salves, or children's vitamins. Now, they also know there are colostomy bags.

Not only are these supplies distributed from the Church, many of them end up in the local hospital or polyclinics where supplies are short.

John Potter

3/25/2014

Hello FOW-USA,

I travelled to Kenya safely and returned to Atlanta this week. On behalf of my sister-in-law Sarah Adhiambo, I wish to sincerely thank you and your organization for the generous donation of ostomy supplies. Sarah will be able to use the supplies for at least 6 months.

God bless you.

Kind regards,
Margaret

E-mails continued on p. 5

Board: FOW-USA



Front row: l-r: Carol Heideman, Al Maslov, Jan Colwell, Nancy Schuller Back row l-r: Ginger Salvadalena, Ival Secrest, Marilyn Zuckerman, Ruth Salinger, Shelly Miller, Richard Cohen
Board of Directors meet. Story p.6

Newsletter Spring 2014

Inside this issue:

P. 2 *Officers and Board
Corporate Support
President's Message*

P.3 *Argentina Adventure*

P.4 *Ostomy Pearls
Warehouse Tour*

P.5 *We Get E-Mails Contd.*

P. 6 *President's Message Contd.
Support Group's Support
FOW-USA Board Meeting
Thank You Supply Donors
Board Member Spotlight*

P. 7 *Upcoming Dates
UOAA Conference
Contributions Form*

Send Supplies

and Contributions to:

FOW-USA

4018 Bishop Lane

Louisville, KY

40218

Tel: 502-909-6669

E-mail:

info@fowusa.org

Website:

www.fowusa.org

Officers and Directors

President

Janice Colwell Chicago, IL

Vice President

Ann Favreau Venice, FL

Secretary

Nancy Schuller Brookfield, IL

Treasurer

Al Maslov Wilmette, IL

Warehouse Coordinator

Carol Heideman Louisville, KY

Immediate Past President

Ival Secrest Sierra Vista, AZ

Directors

Richard Cohen Goodview, VA

Patrick Greco Louisville, KY

Heather Martinek Marlton, NJ

Shelly Miller Palatine, IL

Richard Murahata Denver, CO

Ruth Salinger Bethesda, MD

Marilyn Zuckerman Madison, WI

Honorary Director

Mickey Heideman Louisville, KY

Industry Advisors

Punnie Donohue



Sonia McDonough



Ginger Salvadalena



Newsletter Editors

Shelly Miller Palatine, IL

Walt DeMoss Oswego, IL

CORPORATE SUPPORT

By Marilyn Zuckerman

We are pleased to announce that ConvaTec has awarded a contribution of \$5,000 for operational support to FOW-USA for 2014. These funds will help us fulfill the requests we receive for supplies from ostomy support groups and health centers in developing countries. We greatly appreciate ConvaTec's commitment to helping ostomates throughout the world.

President's Message

Dear Friends,

Friends of Ostomates Worldwide-USA has been fortunate to work with people around the world that share our mission to get ostomy supplies to those in need. Since many of you reading our newsletter have helped to get ostomy supplies to needy ostomates with product and/or monetary donations, I thought you would like to know how others here in the US and outside of the US have helped these ostomates.

A concerned daughter contacted FOW-USA to tell us that her mother in Romania needed ostomy supplies. While the daughter was now in the US, she was looking for a way to help her mother who had just undergone a surgical procedure and needed supplies. Her mother was unaware of resources in her country and our shipping coordinator was able to put her in contact with the Romanian ostomy support group in Bucharest who was able to get her connected with the resources she will need.

We heard from a Filipina whose elder brother had colorectal surgery this February. She was researching using the internet for help in making colostomy bags as the family had no resources to buy the supplies (the only way they were available to her brother). Working with this family, a connection was made with an ostomy worker in the Philippines who FOW-USA has sent and continues to send supplies to exactly for a person like this in need.

A family from Honduras contacted FOW-USA as their sister recently was diagnosed with Crohn's disease and underwent surgery that created a stoma. The hospital where she had the surgery did not have any ostomy bags and the family did not have the financial resources to pay the high price for the products. Working with the family members, FOW-USA volunteers found out the best products for this person and a shipment was made.

The following communication we received from a soldier in Afghanistan and with his permission I am sharing the part of the actual communication (omitting the family name and geographical location):

"Yesterday, we went to one of the nearby villages and met a very nice, but extremely poor family. One of the family members we met was a young man, named Wazir, around 26 years old who lost both legs and part of his stomach from an Improvised Explosive Device (IED) he accidentally walked-on about a year or two ago. As a result, he survived the blast, but has needed to use a colostomy bag for his bowel for the rest of his life. The family is so poor; they were forced to use plastic bags they got from the grocery store and common household tape for adhesive for their son to use on many occasions because they have no money to purchase medical supplies. There is no medical support or supplies available in their village. I'm hoping that your organization might be able to help this poor family in need or re-direct me to an organization that can."

FOW-USA's Argentina Adventure

By Ruth Salinger and Ival Secrest

In the US and other developed countries, most ostomates manage their lives well, including having access to the quality and quantity of supplies they need. In developing countries, however, the story is likely to be very different. Ostomates may not have access to supplies, and the supplies may cost more than is affordable and may be of poor quality. Some ostomates make do with rags, rubber gloves, towels, and plastic bags. Poor skin conditions result; activities are limited or stop altogether, including kids' not going to school and adults' not able to work. Ostomates may be rejected by family and community.

To address these dreadful conditions, the Friends of Ostomates Worldwide-USA (www.fowusa.org) collects donated supplies from individuals and groups in this country, and sends them overseas to ostomy groups, hospitals and clinics, and cancer societies in developing countries. You and your Affiliated Support Group may be among those who help create a quality of life for needy ostomates.

In October 2013, FOW-USA Board members Ruth Salinger and Ival Secrest traveled to Cordoba, Argentina, for a meeting of the Western Hemisphere countries of the International Ostomy Association. (They did so without compensation from FOW-USA.) This meeting of the Ostomy Association of the Americas included representatives of ostomy groups from North, Central, and South America, and the Caribbean. Ruth and Ival talked with these clients, who receive our supplies, as well as gave PowerPoint (PP) presentations to local ostomates and nurses. (See our website for a copy of the PowerPoint.) As most of the attendees spoke only Spanish, we showed the PP in Spanish (and spoke in English!). Multiple participants thanked FOW-USA for the supplies they received, which allowed many of the ostomates in their respective countries to live with dignity.

Traveling to Argentina from the US involved making one or more connections within the US, then traveling overnight to Santiago, Chile, or Buenos Aires, Argentina, then flying to Cordoba, Argentina. For both of us, the trip was well over 24 hours! As experienced ostomates (Ruth for 43 years, and Ival for 36 years), we know about essentials such as taking enough supplies with us in our carry-ons, and emptying our pouches (we both have ileostomies) as needed.



Pictured: Ruth, Martha Velez de Nieves (Puerto Rico), Maureen Flynn (Argentina), and Ival. Martha and Maureen translated between Spanish and English during the conference.

We have also learned to let the airline security officials know that we have an ostomy, which may show up on the scanners.

If they want to pat us down, we let them know where the ostomy is and ask them not to press on it. We also learned – at the 2013 national conference in Jacksonville and through UOAA and Phoenix articles – that the agents may want to take us to a private room and have us rub our hand over the area of our ostomy, then check our hand with a simple procedure. We should not be asked to show our ostomy pouch. (See the website: <http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions>)

Fortunately both of us managed the multiple airlines trips and security checks without issues. Every place is different, however, in terms of rules and processes, and being prepared provides peace of mind. We should point out that security officials in other countries are not required to follow TSA policies but we have found all of them to be courteous and understanding. Good communication is always helpful.

Learning the word for "ostomy" and "bathroom" in the language of your destination is also a good idea. Manufacturers may have offices in these cities, which you can check on their website. Also, the International Ostomy Association may have member groups where you are going: <http://www.ostomyinternational.org/>

So, when you make airline reservations, try to get an aisle seat to go to the bathroom more easily; empty your pouch before boarding the airplane; and don't eat gassy foods before traveling! Go with confidence, and most of all, enjoy yourself!

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

Ostomy Pearls

Peristomal Skin

By Jan Colwell

It is very likely that everyone who has an ostomy will have a complication at one time or another. The complications will most likely have something to do with the integrity of the skin around the stoma. However not all people with a stoma and a complication will be aware that they have a complication as indicated by a recent study published in a medical journal.¹ In this article people with an ostomy were asked to come to the stoma clinic for an evaluation of their peristomal skin. Before they saw the ostomy nurse they were asked if they had any type of peristomal complications. Then the ostomy nurse examined the skin around their stoma and found that well over 45% had complications and that 57% of the patients with a skin problem were unaware that they had a peristomal skin problem. It appears likely that a person with a stoma will at some point have peristomal skin issues and a good assessment of the skin around the stoma should be done on a frequent basis. It also speaks to the issue of what is "normal" peristomal skin.

The skin barrier of the pouching system protects the skin around the stoma. Normal peristomal skin is intact with no open areas and will be the same color and texture as the skin on rest of the abdomen. It is advisable to check the skin around the stoma with every pouching system change. After removal of the pouching system the skin should be cleansed and dried. The skin should be examined to determine if there are any breaks or openings in the skin. A mirror can be used if the skin under the stoma cannot be clearly seen. If a red area is found the area should be touched with a dry finger to see if any moisture is present. Intact skin should be dry, any opening in the skin exposes the second layer of skin that is dermis and this layer is moist. Moisture and a break in the skin indicate that the skin around the stoma has been damaged and needs to be treated.

Damaged peristomal skin can be caused by stool or urine contacting the skin. This damage maybe caused by a poor fitting skin barrier. See our last newsletter (Fall, 2013) for more information on skin barrier fit and wear time. <https://fowusa.org/newsletters/fall2013.html>

Once the cause for the red skin is determined and addressed the skin can be treated and moved toward healing. For superficial skin issues a skin barrier powder can be sprinkled and rubbed into the area and the excess brushed off. Some people will seal the powder and irritated skin with a liquid skin barrier. If the cause is corrected the superficial skin irritation should heal in several pouch changes. If the irritated skin does not improve in several pouch changes contact a certified ostomy care nurse for an evaluation and a plan of care.

References:

1. Nybæk, H, Knudsen DB, et al. Skin Problems in Ostomy Patients: A Case-control Study of Risk Factors. *Acta Derm Venereol* 2009; 89: 64–67.

FOW-USA Warehouse Tour

By Shelly Miller

Thanksgiving, 2013 took on a whole new meaning for me. As part of a 4 person contingent, Board President Jan Colwell, Secretary Nancy Schuller, Volunteer Robin Nasatir and I headed down to Louisville to spend some time at our warehouse to gain an understanding of our operations procedures. It was the first trip to the warehouse for any of us.

Road trips are fun and this was no exception. The 6 hour drive each way seemed to pass in no time as we were all so engaged in conversation relating to our expectations at the warehouse as well as ostomy life. Two Ostomates and two WOCNs; you can only imagine!

Dinner on Sunday was spent with our fabulous hosts, Carol and Mickey Heideman and so much anticipation was conjured up during our meal conversation. But the best was yet to come. We arrived at the warehouse on Monday ready for our tour and prepared to roll up our sleeves and pitch in wherever we could help out.



We were greeted with open arms by our wonderful volunteers. Name badges peeled off from the warmth of the hugs! Each and every one shared with us their stories of why they were volunteering, paying it back as

well as paying it forward. Lunch was the least we could provide these fine folks who give of their time to make sure our mission is fulfilled. Every single one takes such pride in what they are doing and Carol & Mickey have put some great procedures into place in terms of receiving donated supplies, categorizing them, picking and staging the orders and preparing them for shipping. The pride of what we were doing was evident!

We actually brought a truck full of supplies with us from Chicago and processed what we brought so we could experience everything start to finish. We also helped Carol receive some financial donations to get a good idea of how the entire process takes place. Then it was on to picking, packing and shipping orders. Start to finish, we had a good understanding of how FOW-USA operates.

Being Thanksgiving weekend gave us pause to be Thankful for so much and what a GREAT time to extend our thanks to all of the wonderful folks in Kentucky who make us who we are!

Pictured l-r: Carol, Mickey, Robin, Johnda, Joy, Patrick, Shelly, Nancy, Jan

We Get E-Mails Continued

January, 2014

Editor's note: The following email refers to the story in the President's message about a soldier in Afghanistan who is helping a villager.

April 1, 2014

Hi Everyone,

I'm very pleased to inform you that the package you sent arrived safely on March 28th. The items were immediately delivered to Wazir the same day. Wazir and his family were completely overjoyed to receive the donated medical supplies - they were all speechless and overwhelmed with happiness. His brother took a couple of photos for you to use freely for the organization...The supplies you sent were great! The pouch Wazir liked the most was the one sized 44mm with the drain...



Pictured: Wazir receiving his supplies

Kindest Regards,
Dale

July, 2013

Ethiopian Report:

A few people have been trying to form an association of ostomates for some time now. There are still numerous obstacles to cross to get full recognition by the authorities and the members to enjoy the full benefits of assistance from our international supporters. Our efforts are on the way to bear fruit as applications are to be considered at different levels so that the association is, first recognized and second will be able to receive support from any or all friends across the world, unhindered. A few of us met at Black Lion Hospital where most surgeries are done; further treatment and counseling is provided. At the gathering future members (picture above) expressed extreme gratitude to FOW-USA and European Ostomy Association (specifically Mr. Arne Holte and friends in Norway). We are confident that, even as we are trying to be fully legal to receive and share appliances among ourselves and new members, the assistance of our friends will continue even, as ever, individually. We will report progress from time to time as this is a primary mission of the future association.



Pictured: Aberra, Mekonnen, Teferi and clients

Aberra Wolde-Sadik, Ethiopia

Dear FOW-USA:

The Story of an Ostomate

I am a 42 year old man living in a joint family. I underwent ostomy surgery before three months in the Nepal Medical College due to cancer of colon. Initially I was shocked having a stoma. The Chinese one piece closed end pouch was applied but used to leak immediately after its application because of watery stool. I remained about one month's [tolerating] such type of trouble of leakage and frequent pouch change. I had thought that my life is over and going to die soon. "Life was like domestic animals that eat and stay same place where is full of stool and urine". Passing that type of life was my routine for one month. One day, when I asked surgeon for alternative solution, He advised me to meet Ms. Pratima Adhikari for donated ostomy supplies by FOW – USA. Then after, she gave me two piece system drainable pouches which attached for 6 days. After then. I thought that I regained my new life. Also, I conveyed information about the supplies with my friends. So thank you very much FOW USA for doing such a great work for the betterment of our life. Really hearty thanks and wish you all a "Happy New Year".

Shared by Pratima Adhikari, a volunteer at Choice Humanitarian, a non-governmental organization in Nepal

 **edgepark**
Medical Supplies



The Edgepark Advantage

- ✓ We handle all the prescription and insurance paperwork for you
- ✓ FREE shipping in 1 – 3 business days (after order processing)
- ✓ We offer the widest breadth of products, so you get the brands you want
- ✓ We accept Medicare and 1,200 health plans, to maximize your benefits

Call or go online to place an order today!



1-800-321-0591

8 a.m. – 10 p.m. EST, Monday – Friday
9 a.m. – 3 p.m. EST, Saturday



www.edgepark.com

Secure and convenient
ordering, anytime!

President's Message cont'd

Continued from p. 2

We sent a communication that FOW-USA would be able to provide assistance and here was his reply: "After receiving your email this morning, I met with his younger brother Aziz, who works in the small grocery store and he began to cry because he was so overwhelmed with happiness to know that his brother would soon receive ostomy medical supplies.

Aziz makes almost \$300 a month as a clerk and supports a family of five people as the youngest son. The women in his family and in Afghanistan society traditionally do not work. I am simply amazed at how resilient and resourceful the Afghan people are with surviving on such a low income. Seeing Wazir up close and personal truly puts life into perspective and makes me realize just how fortunate we are to live in a modern society with basic medical care available."

It is hearing the personal stories such as these that let us know how important the work that we do is to so many people. We want those of you who support us to know what the impact of your product and financial donations has on people around the world. Thank you for your help and we hope you can continue to support FOW-USA's mission.

Jan

Support Group's Support

By Ann Favreau

I just returned from facilitating a meeting of the Venice, FL ostomy support group. At the beginning of the meeting I gave a short talk about the work of FOW-USA using the stories about mothers and children provided to me by Ruth. Then I presented the Champion a Child for Mother's Day project and sent around a large envelope reminding folks that this was simply a voluntary donation that they could choose to make or not. We had 14 people at our meeting. When the envelope returned to me, I placed it in my folder because we were in the middle of a sharing session. A long time member came up behind me and whispered that she would like me to fill in the name of the organization on a check. As I reached for my pen, I looked in amazement. The check was made out for \$100. By this time she had gone back to her seat. At the close of the meeting, I thanked her for her generosity. "You touched my heart," she said. "I wanted to do this." I have to tell you that I have goose bumps writing this email. In addition we collected \$77 and some people wanted to know if they could contribute next month because they didn't come prepared. I will send this lady's check in now and the remainder of the donation after next month's meeting. Putting a face on the work of FOW-USA through stories resulted in generous hearts.

FOW-USA Board Meeting

On Sunday, March 30, the FOW-USA Board of Directors convened in Louisville, Kentucky, for its annual in-person Board Meeting. The Board meets via Conference Call every other month during the year. At the March meeting, which was the first at the new warehouse in Kentucky, the Board accepted nominations for new Officers and Board Members, discussed the success of the October fundraiser and possibility of another in the Fall of 2014, discussed the new database project and new website, appointed the people who will do the website updating, reviewed the most recent Shipping Report, and addressed all other issues necessary for the successful operation of FOW-USA. Our Fundraising, Public Relations and Finance Committees have been hard at work and all reported on their activity.

Some key FOW-USA activities this year include participation in regional WOCN meetings, continuing to have a presence in Social Media, completing the database project and a major emphasis in obtaining email addresses for our newsletter distribution to help save much needed funds for shipping products.

Thank You Ostomy Supply Donors

We are grateful to everyone who donated ostomy supplies to FOW-USA during the past year. Space limitations prevent us from printing the names of all the donors, but without your generosity we would not be able to provide ostomy products to developing nations around the world. Thousands of ostomates have benefitted from your generosity. Keep sending those ostomy pouches, face plates, powders, belts, skin products, tape, and other items, and especially pediatric supplies to our warehouse at:

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

Board Member Spotlight

Welcome our newest Board Member, Patrick Greco. Patrick is a retired Information Technology manager who worked for several large international companies including General Dynamics and IBM. Patrick's volunteer work is guided, inspired, motivated and in memory of his wife Marie. Marie passed away from Crohn's disease in 2013; she was a loving beautiful person who inspired everyone she met.

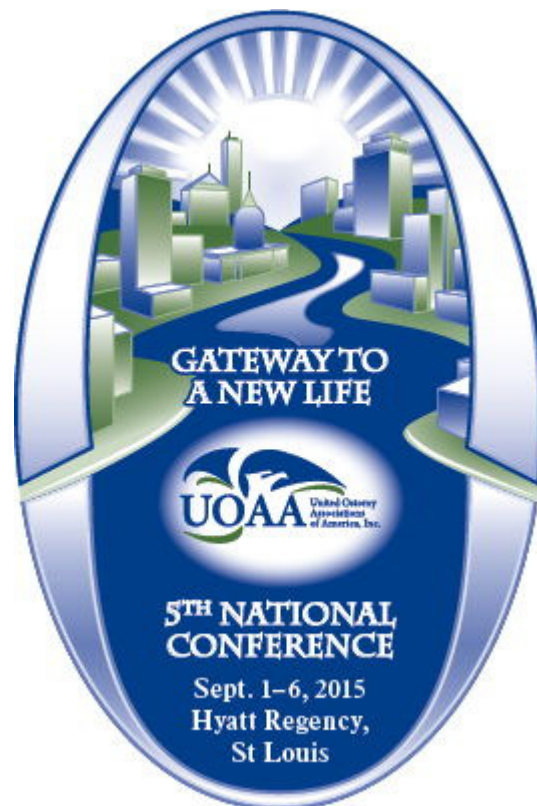
In addition to volunteering at the FOW-USA warehouse he has offered to help the Crohn's and Colitis Foundation of America with the 2014 Take Steps team walk scheduled for later this year. As Patrick attempts to continue Marie's legacy and patient advocacy, he is always looking for ways to improve the quality of care being received for both patients and family members.

Help Save FOW-USA's Budget and the Environment!

Request your FOW-USA Newsletter by e-mail. It's free, in color, and quicker than snail mail.

Go to our website. www.fowusa.org and sign up on the first page OR langsecrest@yahoo.com. You'll save us money and help us ship more supplies overseas to meet the needs of ostomates.

Save the Date!
Mark Your Calendars!
Visit us in St Louis!



Visit our booth at these upcoming Meetings:

UOAA Mid-Atlantic
Regional Conference
May 2-4, 2014
Dulles, VA

WOCN Society's 46th Annual Conference
June 21-25, 2014
Nashville, TN

North Central Regional WOCN Conference
September 19-20, 2014
Rochester, MN

Northwest Annual WOCN Conference
September 25-27, 2014
Seattle, WA

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 and click on Donations.

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

Address Service Requested

Spring 2014 Newsletter

