By Lou Wray

In the 1970’s as U.S. ostomy doctors, nurses, medical professionals, and ostomates traveled abroad, they returned home with stories of the horrible conditions endured by patients in developing countries following ostomy surgery. People were using tin cans, rags, and other such materials to cover their stomas. Ostomy supplies were not available. There was no odor control and ostomates were ostracized. Soon after, several United Ostomy Association (UOA) chapters and individual members began soliciting for and gathering ostomy supplies and sending them to places known to be in great need such as Mexico and Colombia. Archie Vinitsky, past UOA president and first president of the International Ostomy Association (IOA), and others began to urge organization leaders and equipment manufacturers to recognize the terrible plight faced by ostomates abroad and to send ostomy supplies to these less fortunate ostomates.

In 1980, the IOA applied for a new charitable corporation to be named Friends of the International Ostomy Association (FIOA). The purpose of FIOA was “to seek dues and donations to support the work of the IOA in promoting the health and rehabilitation of ostomates.” FIOA, the forerunner to Friends of Ostomates Worldwide (FOW-USA) was charged with fundraising for Project SHARE (Sending Help and Rehabilitation Everywhere).

At UOA’s Toronto conference in 1986, several past UOA presidents were invited to a special meeting to discuss more active involvement with FIOA(US). It was agreed that the establishment of a collection center and a volunteer group to pack supplies was priority number one. Soon after the conference, Steve Lutz of the Cleveland Ostomy Association agreed to provide space for an ostomy supply collection center in his machine shop in North Ridgeville, Ohio. Volunteers from northern Ohio UOA chapters were recruited for packing. This was the start of FOW-USA, although not yet in name.

In 1987, the IOA Board recommended that FIOA be operated by the International Relations Committee of UOA, rather than by IOA. This was continued for 4 years. Although it had been operating since 1986, by-laws and incorporation papers were drawn up for Friends of Ostomates Worldwide-USA (FOW-USA) in 1991. It became incorporated as a non-profit tax-exempt organization to implement Project SHARE. Continued on page 3

We Get E-Mails

Dec. 17, 2010

Dear FOW-USA:
...I am from the new staff of Kyra [clinic in Guatemala], I am a General Practitioner...a story from one of our patients: A 35 year old female was born with congenital anomalies...She has been operated seven times along her life, and that is why she need to wear the pouches/barriers, etc. for the colostomy.

Sincerely yours,
Dr. Aleyda Monzon, Guatemala

Dr. Aleyda Monzón with ostomate

Send Supplies and Contributions to:

FOW-USA

1500 Arlington Ave.
Louisville, KY 40206-3177

Tel: 502-736-6360
E-mail: info@fowusa.org
Website: www.fowusa.org
Dear Friends,

I’ve served five eventful years as the president of FOW-USA. This will be the last time I write as president because it is now time for me to move on and let another person take over with new ideas and new objectives. I have served on the FOW-USA Board continuously for 15 years, since Norma Gill Thompson called me in 1996. What a spunky woman! We did not have an internet presence in 1996 and all letters were written on a typewriter with the database on 3x5 cards.

I would like to publicly thank my friends and relatives who have supported me and FOW-USA with their financial contributions to FOW-USA. You know who you are and I appreciate you very much.

Yes, things have changed because we have had several “change” agents on the board and hopefully I was considered one of them. When I accepted the gavel from Fred Moore in 2006 we were collecting, sorting and shipping supplies in Glenview, IL. Volunteers had to be at the facility M-F and there were insufficient volunteers to do that without burnout. In early 2008 we moved the operation from Glenview to Louisville, KY and located with another non-profit organization, Supplies Over Seas, who have a warehouse manager that opens and closes the facility M-F. Thanks to the Louisville Affiliate of the United Ostomy Associations of America (UOAA), we have volunteers who come in once each week to receive donated ostomy supplies, sort the supplies and then pack for shipment to countries where the need is greatest. To use an old saying – They are a Godsend.

We have changed things administratively in that the work is spread among several people instead of just a few. The objective of this change was to minimize burnout. Instead of a person at the collection facility and one somewhere else, we have the administrative tasks being accomplished by six people in six different locations – thanks to electronic communications.

We have added to the functionality of our website so we can accept financial contributions online and have a place for viewers to request an electronic copy of our newsletter. The number of people requesting information via the website has increased dramatically. It is important for us to be aware of our technology-oriented society and advance with them to the extent possible.

Last year I was writing about the devastation and need in Haiti. We have received several inquiries about the need in Japan following their earthquake. There is a stark difference between a developed country like Japan and a very poor country like Haiti. Japan has been able to take care of their own ostomates and even help other Asian countries whereas Haiti desperately needed supplies and assistance. Poor countries that also have political strife most often need supplies and assistance for their ostomates. You can read how we are assisting some of those countries elsewhere in this newsletter and also on our website.

We would appreciate your dropping by our booth at the Wound, Ostomy, and Continent Nurses (WOCN) Conference in New Orleans in June and/or our booth at the UOAA Conference in Reno in August. It is time to say good-bye as president of FOW-USA and thank everyone for their support of FOW-USA.

Ival Secrest
The first significant shipments made by Project SHARE were in Fiscal Year 1989. Over 12,000 pounds of supplies were shipped to 5 countries: Brazil, Argentina, Algeria, Malaysia, and India, at a cost of $8,000. The number of countries served grew each year, as did costs. By its 10th anniversary, in 1996, 11 shipments were made to Thailand, Peru, Vietnam, Latvia, Jamaica, Bosnia, China, India, Chile, Argentina, and El Salvador. In Fiscal Year, 2010 FOW-USA made 39 shipments to 22 countries, at a cost of $26,000. Since its inception, FOW-USA has shipped almost 256,000 pounds of supplies to 65 countries around the world, at a shipping cost of $287,000. The estimated retail value of these supplies is almost $12 million. The value to ostomates in need around the world is priceless.

The response to appeals for clean unused appliances was overwhelming and soon a larger space was needed. Again, Steve came to the rescue, moving his business to an Elyria, Ohio, site providing more room for further growth and expansion. After several years, that space became unavailable and the warehouse was relocated to a smaller location back in No. Ridgeville. Then Lou and Rita Wray obtained a large secure warehouse site, free of charge, in Akron, Ohio.

Recipient countries were identified by FOW-USA volunteers and members, UOA and IOA members, and manufacturers. FOW-USA required that an organization such as an ostomy association, hospital, clinic, or responsible medical professional would be able to receive and store the supplies as well as distribute them to needy ostomates free of charge. Shipping was by air, sea, or land depending on the recipient country’s location.

Ostomy supplies were and still are donated by ostomy associations, hospitals, pharmacies, manufacturers and individuals. Donors ship the supplies to the FOW-USA warehouse at their own expense. Financial contributions are solicited through mailings, exhibits at conference booths, and semi-annual newsletters. An elected Board of Directors oversees the operation of FOW-USA. With no paid staff, volunteers have always been the backbone of the organization.

We Get E-Mails continued

Dec. 12, 2010

Dear FOW-USA:
I have met the representatives of the government hospitals today and we had a fruitful meeting. They extend their gratitude to FOW-USA and they are very happy with the donation. It is very clear to them that it will go to the most needy and indigents of their respective hospitals. They have mentioned that some ostomates still use the nescafe lid and a plastic bag.
The appliances will be a big help...they will start an ostomy club in their hospitals too as a support group. I plan to have the distribution of the supplies printed in the local newspaper to further promote the advocacy.
Hope you are in the best of health. Thank you very much.

Sincerely, Ronaldo Lora, Philippines.

(Ronaldo, in wheelchair, and colleagues with FOW-USA supplies)

Jan. 27, 2010

Dear FOW-USA:

We received the bags today. Thank you very much. Please thank...[the FOW-USA] staff for me. We are in the process of letting our clients know that our stocks have arrived and they are most relieved.

Kindest regards,
Sonjette Rodriguez
Saint Lucia Cancer Society

25th Anniversary continued

The response to appeals for clean unused appliances was overwhelming and soon a larger space was needed. Again, Steve came to the rescue, moving his business to an Elyria, Ohio, site providing more room for further growth and expansion. After several years, that space became unavailable and the warehouse was relocated to a smaller location back in No. Ridgeville. Then Lou and Rita Wray obtained a large secure warehouse site, free of charge, in Akron, Ohio.

Continued on page 7
Have you ever wondered if FOW-USA and FOW-Canada (FOWC) are the only organizations sending ostomy supplies to those in need in developing countries? The answer is that many other nations also send supplies to places of need and many also provide additional support to ostomates. Some examples are listed below, thanks to Di Bracken of FOWC:

- The Australia Fund is “twinned” with Indonesia and sends ET support as well as supplies.
- New Zealand is twinned with Nepal and an ET visits regularly providing support.
- New Zealand and Australia work in the Polynesian Islands.
- Japan is twinned with Mongolia and visits, does training, and provides supplies.
- Deutsche (German) ILCO supports the Ukraine in training doctors and nurses and providing supplies.
- Swedish ILCO is supporting Zimbabwe.
- Norway is twinned with St Petersburg, Russia.
- For many years the United Kingdom has been twinned with Romania working on a number of fronts.
- FOWC is involved with many countries and recently shipped supplies to Kenya, India, and Moldova.

This information may explain why FOW-USA sends supplies to certain countries and not others, as we do not want to duplicate efforts.

Louisville, KY, volunteers at the FOW-USA warehouse donate over 1,500 hours each year, unpacking, sorting, repacking and shipping supplies.

We are very grateful for their generous contributions.

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**IOA Congress**

By Ruth Salinger

I attended the 13th Annual Congress of the International Ostomy Association (IOA) in Frankfurt, Germany, November 18 – 21, 2010, representing FOW-USA.

There were two purposes in my participating:

1. Connect with client countries – past, current, and potential future ones.
2. Learn about the changes in the structure of IOA.

I talked with individuals and groups before and after meetings, and during meals. The individuals included delegates from Mexico, Puerto Rico, Argentina, Bolivia, Brazil, Chile, Colombia, Mongolia, Spain, Norway, Sweden, Lebanon, and the Philippines. I also spent time with representatives from the USA (UOAA), Canada, Australia, and New Zealand. The presidents of the various regions were also among my contacts. Finally, my thanks to Alexander Machaca of Bolivia for arranging a meeting with delegates from the South American group to learn about their specific needs for ostomy supplies.

The IOA discussed and approved a major reorganization of the organization. Instead of 6 regions, the IOA will have 3 regions: the European Ostomy Association, the Asia Pacific Ostomy Association (APOA), and the Ostomy Association of the Americas (OAA). There will be no future meetings of the IOA as a whole body as each region will have its own meetings every two or three years. Conference information was put on a disc, which included a one-page description of FOW-USA.

This was a most beneficial meeting for FOW-USA as the purposes for my participation were successfully met.

(Ed. Note: Ruth Salinger paid all her own expenses to attend this meeting on behalf of FOW-USA)

(Ruth, third from left, with members of the South American delegation)
In the first eight months of FY2011, FOW-USA has made 21 shipments, totaling 5,084 pounds, destined for 14 countries, with a retail value of over $256,000.

Several shipments were made to individuals and organizations in the US who will deliver the products to designated countries through their travels and/or humanitarian work. By working with these partners, FOW-USA ostomy supplies can reach more ostomates in need at a lower cost.

Countries served so far this year are: Argentina (2 groups), Belize, Bolivia, Chile (2 groups), Colombia, Ecuador, Ethiopia (2 groups including the Fistula Hospital), Lebanon, Nigeria, Nepal (2 groups), St. Lucia, Trinidad and Tobago, Zambia, and Zimbabwe.

The United Ostomy Associations of America (UOAA) will hold its biennial conference from August 7-11, 2011 in Reno, NV. FOW-USA will hold its Board Meeting at the conference, on Monday, August 8. We will have a table in the exhibit booth area where our Board members will answer any questions and provide information about FOW-USA. The FOW-USA program will be on Thursday, August 11 and will feature well-known speaker and author, Brenda Elsagher. A cancer survivor and ostomate, Brenda finds humor in everyday experiences. Her books include, I'd Like to Buy a Bowel Please! We hope you will join us at the conference for one or all of our events. We look forward to seeing you there.

For more information about the UOAA conference, go to www.uoaa.org.

NEW BOARD MEMBER

Joan Countess has recently been appointed as an FOW-USA Board member. She is an ileostomate, a member of UOAA and the President of the Heart of Texas Ostomy Support Group. She has been a member of a support group since 1990. After moving to Brownwood, Texas in 1997 she discovered there was not a support group within 80 miles. After two years of trying to get a group started, she was successful in starting a satellite chapter under UOA. Today that chapter is an Affiliated Support Group under UOAA. She and her husband, Bill, are retired. Much of her time is spent in volunteering at church.

When you donate ostomy products to FOW-USA, please check the expiration date. The customs officials in foreign countries are not aware of our supplies and how well they last. Therefore, when they check a shipment, if one item has an expired date, the entire pallet of supplies or shipment is thrown out. We know that no one wants that to happen.

There has been some confusion regarding expiration dates on materials sent to the warehouse. Some companies make the expiration date very clear, and you need to allow at least six months from when you mail the supplies to FOW-USA and the expiration date. Please look for these dates.

Convatec products have the expiration date in code. The first number is the year it was manufactured, and items have a five year life span. The first letter is the month of the year. For example, 4A7947 expires in 2009 (the 4) in January (the A). Likewise, C is for March, F is for June, J is for November and so on. In the same way, a 5 expires in 2010, a 6 in 2011 and so on.

We all realize that many products are excellent to use after their expiration date. However, while the warehouse can discard expired items, it makes everyone sad to know that some of you are paying postage on items we can’t use. Your money and your supplies are too valuable. Remember that the postage costs to send us supplies are tax deductible.

We do appreciate your cooperation and generosity when sending us supplies. Thank you.

Send Ostomy Supplies to:
FOW-USA
1500 Arlington Avenue
Louisville, KY 40206-3177

Correction

FOW-USA regrets the omission of Ruth and Russell Balise from our list of supply donors in the Fall 2010 newsletter. Thank you Ruth and Russell and all the supply donors.
Thank you to all those listed below who have contributed to FOW-USA during the past fiscal year. If you are not on the list and should be, or if your name is spelled incorrectly, please e-mail contributionssecretary@fowusa.org.

**FOW-USA FINANCIAL CONTRIBUTORS Aug. 1, 2009 thru July 31, 2010**

**Grant**
ConvaTec
The International Foundation

**Memorial**
Mrs. Mary DiLuna

**Benefactor**
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**Chapters/Support Groups**

**AL**
UOAA, Huntsville

**AZ**
Tucon Ostomy Support Grp.
Southeast AZ Ostomy Assn.

**CA**
Orange Co. Ostomy Assn.
Ostomy Assn. of San Diego

**CT**
Ostomy Assn. Of Central CT
So. Fairfield Co. Chapter

**FL**
UOAA of Greater Orlando

**IL**
DuPage Co. Ostomy Group
Ostomy Assn., Of Grtr. Chicago
Quad City Ostomy Group
Sterling Area Ostomy Assn.

**KS**
Dodge City Area Chapter

**KY**
Kentuckiana Chapter UOAA

**MD**
Anne Arundel Co Ostomy Assn

**MI**
Ostomy Assn. Of Grtr Lansing
Macomb Co. Ostomy Assn.
Straits Area Ostomy Assn.

**MN**
Duluth Area Ostomy Group
St. Paul Ostomy Assn.

**NE**
North Platte Area Chapter

**NJ**
Morris Co. Ostomy Assn.
Warren Co. Ostomy Club

**NY**
Colostomy Society of NY
Grouse Hospital Ostomy Grp.
Ileostomy Society of NY
Schenectady Ostomy Sup Grp

**OH**
Akron Ostomy Assn.
Grtr Cincinnati Ostomy Assn.
Ostomy Support Grp, Dayton
Lorain Co. Ostomy Assn.

**PA**
Pittsburgh Ostomy Society

**TN**
Chattanooga Ostomy Assn.

**TX**
Central TX Ostomy Sup WACO
Ostomy Supp Assn, Ft. Worth
Longview Ostomy Supp Grp
Ostomy Assn. Of West TX

**WI**
Chippewa Valley Ostomy Assn.
The FOW-USA warehouse moved from Akron to Glenville, IL, in 2001, thanks to the efforts of Joan Loyd, and in 2008 to Louisville, KY with the help of Stuart Grossman. New cadres of volunteers to pack and ship supplies were recruited in each location. FOW-USA partners with Supplies Over Seas (SOS) in the operation of the Louisville warehouse.

Over the years, additional items, such as ostomy manuals, films, educational materials for doctors and nurses, and video cameras for the training of nurses and patients were provided. Although Project SHARE remains its primary activity, the organization has become known to the public as FOW-USA rather than Project SHARE. Its mission is “to provide ostomy supplies and educational materials to help ostomates in need around the world.”

While ostomy supply shipments from FOW-USA have been a great help to thousands of ostomates, many additional benefits have resulted from this operation, such as the formation of ostomy self-help groups in recipient nations, more training of ostomy nurses, and a greater awareness of ostomy needs around the world. We look forward to the next 25 years of meeting ostomate needs. Unfortunately, in some countries, many ostomates still resort to cans and rags to cover their stoma. In a more perfect world, the need for this organization would decline as nations become able to provide ostomy supplies for their citizens who need such help. Until that time, FOW-USA stands ready to help, thanks to the generosity and dedication of its volunteers, supply donors and financial contributors.

---

**LETTER FROM A SUPPORTER**

4/3/11

Dear FOW-USA:

...While I can’t afford to donate to as many organizations that I would like to, FOW-USA is the only one that I make sure I donate something annually. I have had an ileostomy since 1975 and have been fortunate (most years) to have medical insurance that covers at least some of the cost of my ostomy supplies. It is painful to think of people that have no access to ostomy supplies. It also amazes me that some of these individuals have had the strength and wherewithal to heal from the surgery needed.

As always, thank you and all of the volunteers for your good works to help ostomy patients worldwide. I feel confident that the organization continues to assess situations as much as possible and to use donations wisely. My best wishes to all involved.

---

**Friends of Ostomates Worldwide—USA Contribution Form**

Name______________________________

Address______________________________

City State Zip__________________________

Country______________________________

Telephone (____)_______________________

E-mail Address ________________________

**Giving Level**

- Partner-$50
- Corporate-$300
- Sustaining -$75
- Benefactor-$1,000
- Contributing-$150
- Lifetime/Memorial- $5,000
- Supporting-$300
- Other-$___________

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

FOW-USA, Attn: Treasurer, 1500 Arlington Ave, Louisville KY 40206-3177

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

*To Donate On-Line: Go to www.fowusa.org and click on Donations.*
FOW-USA
1500 Arlington Avenue
Louisville, KY 40206-3177
USA

Address Service Requested

Spring 2011 Newsletter