Dear Friends,

Each time I read a response from one of the recipients of the ostomy supplies that we have shipped, it touches my heart. To realize that FOW-USA has the ability to enhance the life of an ostomate is such a worthy endeavor. Our mission has continued for 30 years. That, in itself, is a milestone. From August 2015 to March 2016 we have shipped over 9,000 pounds at a cost of approximately $21,000. The estimated retail value is $450,000. The value to each person who receives the supplies is priceless. We can only do this with your support. You are helping our board and volunteers to make a difference every day.

As a result of our strategic planning we are enhancing our technological abilities. Nancy Gutman has led a team to get our new data base up and running. She has worked tirelessly to learn this new system and has coordinated its many functions. We are now able to send appeals and the newsletter by email. This has saved us dollars which we can use to ship products. Mickey Heideman, our Treasurer, has developed a process for mailing appeal letters and the newsletter that is more efficient and cost effective. He continues to streamline the operations of the warehouse. Carol Heideman, our Warehouse Coordinator, has secured new volunteers to help with the work of unpacking and repacking the products that are sent and Cheryl Sparks acknowledges product and financial contributions.

FOW-USA has an educational component to its mission. This year we are supporting the efforts of Drs. Carlo Pezcoller and Harikesh Buch in the Lions for Stoma Care Project to train nurses from developing countries in the care of ostomates. Jan Colwell has also sent them copies of the book she coauthored, WOCN Core Curriculum, Ostomy Management.

We have many people who help us with our public relations efforts. Lauren Beatty, a volunteer, has updated our website to a new platform and we are in the process of refining the text and images. UOAA continues to feature our message on their home page and distributes a quarterly article to their 350 affiliated support groups. Ruth Salinger and I were pleased that an article that we wrote about FOW-USA received a two-page spread in the Ostomy Canada magazine. When we are able to talk to people about FOW-USA, it extends our outreach. Lang Secrest did so at the March 5th Phoenix Ostomy Education and Supplier Fair. Cindy Barefield staffed our booth at the WOCN South Central Regional meeting in Branson, MO. Jan Colwell, our Past President, travelled to South Africa to meet with Wound Ostomy Continence nurses and Mr. Joserf Muchesa, the managing director of the Ostomates Zimbabwe Support Trust, a group that has received FOW-USA donations. (See story on pg. 4). In addition she attended the World Council of ET nurses. In April, Ruth Salinger, our Shipping Coordinator, will talk with attendees at our table at the UOAA Mid Atlantic Regional Ostomy Conference. Through these interactions we are able to garner interest in our mission.

At the time of this writing, our Newsletter was getting a “makeover”. Hope you like the new format! I am grateful for your donations that help us serve the needs of ostomates worldwide.

Ann

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E-mail us at info@fowusa.org
Meet our Officers & Board of Directors

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Ann Favreau   Venice, FL

Vice President
Shelly Miller   Palatine, IL

Secretary
Nancy Schuller   Brookfield, IL

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Mickey Heideman   Louisville, KY

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Cindy Barefield   Mont Belvieu, TX
Dawn Becker   Brewster, NY
Nancy Gutman   Botkins, OH
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Richard Murahata   Denver, CO
David Rudzin   Vernon Hills, IL
Ruth Salinger   Bethesda, MD
Cheryl Sparks   Louisville, KY
Linda Stricker   Westlake, OH

Industry Advisors
Rebecca Wright
Sonia McDonough
Ginger Salvadalena

Newsletter Editors
Ruth Salinger   Bethesda, MD
Shelly Miller   Palatine, IL

Board sets 2016 Schedule

The FOW-USA Board of Directors held its live, face to face, annual meeting in conjunction with the UOAA Conference in St Louis, MO last fall and set the schedule for our bi-monthly conference calls, committee meetings and 2016 annual meeting. Every other year we arrange to meet in Louisville, KY to enable us to spend time at the warehouse. This year the meeting is to be held October 16, 2016 in Louisville, KY. Many of the board members opt to stay an extra day and reconvene at the warehouse first thing Monday morning, to roll up their sleeves and assist the wonderful volunteers for a day. It is always wonderful to meet the faces behind the scenes who work tirelessly to achieve our mission and unpack, sort, stock and reship the products around the world.

Our agenda is always full and we return home with a renewed sense of accomplishment that what we do as a group is so worth it! And none of it is possible without YOU! Your financial donations and donated supplies are what keep the mission moving forward! Thank you!

We remember Stuart Grossman, former Board Member

FOW-USA mourns the passing of former member, Stuart Grossman. Stuart helped move the warehousing of supplies from Ohio to Illinois in 2000 and his knowledge of the Louisville, Kentucky area ultimately led to him assisting in the move from Illinois to our facilities in Kentucky. Stuart had the local Louisville ostomy support group under his wing and they had confidence in Stuart so they have been doing the "heavy lifting" of unpacking, sorting, packing and shipping. Stuart provided wise counsel about the local people regarding their existing commitments, their abilities and their ability to work with others. He recommended Carol Heideman; she was asked to run the warehouse and ultimately Stuart implied that Carol’s husband, Mickey, had shipping connections that would help get the best possible rates for shipping for FOW-USA. Stuart’s vision of FOW-USA in Louisville has blossomed because of the wonderful volunteers who understand commitment. He was very instrumental in getting us up and running in our new digs as well as having the connections with the right people to get the job done. FOW-USA offers Stuart’s family and friends our heartfelt sympathy.
The issue of stigma is explored in The Phoenix (June/Summer 2015) edition. Having the perception that you are socially unacceptable is self-stigma. Without intervention, self-stigma can lead to non-compliance with treatment, negative effect on well-being and possibly thoughts of suicide. Fortunately, family, friends, and health professionals can provide coping strategies to lessen the social isolation, withdrawal and loss of hope that comes with self-stigma. A recent pan-European study reported improved quality of life for ostomates receiving support from an associated group of patients. One ostomate made this statement about the ostomy support group he attended: "The people who now support me help me to feel good about myself. They are the bridge that unites my past experiences with my present life..."

Researchers studied ostomy patients and their range and intensity of negative responses to offensive events. They wanted to know if this would help predict the extent to which the individual could adapt to life with the challenges of an ostomy: odors, gas noises, possible leakage, and contact with feces. Interestingly enough, researchers found that those who were less likely to adapt to these challenges anticipated that others would react adversely to these challenges as well. This was also a strong negative predictor of adjustment and well-being following ostomy surgery. Is life with an ostomy a self-fulfilling prophecy?

It did not seem to limit the accomplishments of these famous ostomates: Dwight D. Eisenhower (34th President of the USA), Rolf Benirschke (placekicker for the San Diego Chargers in the late 70’s & 3rd most accurate NFL kicker in history), and Napoleon (military general & first emperor of France). A self-fulfilling prophecy is a belief that comes true because we are acting as if it is already true. Rolf Benirschke says it best, "Things really can work out if you embrace life!"


Ostomy Pearls—When Self Fulfilling Prophecy Overcomes Adversity! Cindy Barefield, BSN, RN-BC, CWOCN

Cindy Barefield is a certified Wound Ostomy Continence Nurse (CWOCN) who resides in Mont Belvieu, TX. As an experienced nurse in Staff Development, Cindy developed a passion for ostomy care with consults for the education department to teach new ostomates. After completing the MD Anderson Wound Ostomy Continence Nurse Education Program, Cindy has worked as a WOC nurse for Houston Methodist San Jacinto Methodist Hospital in Baytown, Texas for the past 12 years. Cindy established and continues to facilitate a monthly UOAA support group for the community.

Cindy and her husband have 2 children, 27 and 23 years of age and one grandson, age 4 who loves the Avengers!

Dawn Becker was diagnosed with Ulcerative Colitis in 1988 at the age of 20. Before this diagnoses however, things were hard. Going to doctor after doctor, being told there was nothing wrong, and being sent back home. However after many years of struggling and finally getting an answer, she was relieved. After she got the surgery in 1992 things were finally bright again. Since then she has become happily married and has 4 beautiful children. She is a business owner, an entrepreneur, and a runner, participating in several half marathons. She says that life is good and is honored to be a part of such a wonderful organization! Dawn has been assisting FOW-USA by doing all of the answering machine intake and response!

Cheryl Sparks was married for 50 years to her husband Ron, who unfortunately passed away last year. They have a daughter Carin, and have two grandchildren, Hayden and Libby.

Diagnosed with stage IV anal cancer in 2001, surgery to remove it left her with a colostomy. Cheryl felt it was not a huge issue and that she adjusted well and that Ron was such a supportive part of her healing process. Having a newborn granddaughter and a very funny two year old grandson who loved to hear Gramma toot in her pouch helped, too. It was then she joined the local Louisville Ostomy Group and has been working for and with this group since then serving as President, Newsletter Editor, as well as most of the visitation for the past five years. Cheryl also worked full time at the Arch L. Heady Funeral Homes in Louisville since 1985 as office manager and did whatever needed to be done to help families get through the tough process of burying their loved one.

Still there part time enables her to work two days a week at the FOW-USA Warehouse where she does all of the work of our volunteers and also assists our Warehouse Management with the donation acknowledgements.

She says, ‘I am honored to be on the board of the FOW-USA. Though it is very daunting, I hope I can be of some use to the board in working to keep the warehouse as the wonderful place it is, and doing the job of getting these supplies where needed.”

Board Member Spotlight

Cindy Barefield

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“Things really can work out if you embrace life”
Our volunteers come from ostomy clubs, industry and church groups, to mention a few.

Small is Beautiful

FOW-USA was founded more than 30 years ago by members of the UOA as part of Project Share with the intent from the beginning to create a totally voluntary organization, managed and financially supported by members of the UOA.

FOW-USA would demonstrate to the world the gratitude of those who survived their medical ills and regained their life. During these years, the FOW-USA has met its mission by providing ostomy supplies, educational materials and, most importantly, hope to hundreds of thousands of persons around the world.

This was possible through the generosity of many individuals who contributed money, supplies and time. With this support, FOW-USA has maintained its operations continuously these many years, first in Ohio, then in Illinois and now in Kentucky. Volunteers from ostomy clubs, industry and church groups to mention a few, would come to the warehouse regularly and work, unpacking, inspecting, packing and shipping supplies.

This successful effort was underwritten by and large by many individuals who gave small donations that enabled FOW-USA to pay for its warehouse space and shipping costs without interruption for more than 30 years. And because FOW-USA is a totally volunteer organization, ninety-nine cents of every dollar goes to meet the needs of ostomates in developing countries around the world.

If you believe that small can be beautiful, donate a small amount to the FOW-USA and help us meet this important mission.

FOW-USA visits South Africa

I recently made a trip to South Africa and while there attending a meeting, on Friday March 11, 2016, I met with Joserf Muchesa, founder of the Ostomates Zimbabwe Support Trust. He had ostomy surgery at age 15 and had his stoma closed after one year. He identified the need for stoma education as well as the acquisition of ostomy supplies. Along with Mr. M Munyoro and Nurse Frances Desales Misi he worked on developing the Ostomates Zimbabwe Support Trust to provide education, support and products to people who have an ostomy. His group provides services to approximately 47 people in Zimbabwe that would have no other means to acquire ostomy supplies. He has met people in his country who tape a piece of plastic over their stoma to try and contain the stoma output, an inadequate management system but all that some people in Zimbabwe have at their disposal. Friends of Ostomates Worldwide - USA has provided Ostomates Zimbabwe Support Trust with supplies to help the people in Zimbabwe adequately manage their stomas with odor proof pouches that protect the peristomal skin and allow them to return to their normal activities.

Joserf and I talked about the challenges in helping people manage their stoma and the need for an educated stoma nurse. Ms. Frances Desales Misi works with the people who come to the Support Trust but would like to have formal education on stoma care. When I met Joserf he was getting ready to attend the World Council of Enterostomal Therapy meeting in Capetown, South Africa and to meet several Enterostomal Therapists who have developed stoma educational programs. It is his hope that he can find support for Ms. Frances Desales Misi to attend an enterostomal therapy educational program that the World Council of Enterostomal Therapy provides and bring those skills back to Zimbabwe to become the first enterostomal therapy nurse in Zimbabwe.

It is exciting to see the enthusiasm, energy and commitment that Joserf has for developing ostomy care services in Zimbabwe. He traveled over three days in a bus to attend the meeting of the World Council of Enterostomal Therapists. I was very pleased to meet Joserf and receive his thanks for the FOW-USA donations. I brought him several FOW-USA tee shirts and pens as well as the stoma pins that the United Ostomy Associations of America donated. To start the movement toward stoma nurse education, I provided him with a copy of the new Wound Ostomy and Continence Nurse’s ostomy curriculum book that can serve as a resource for his group.
We get E-mails (cont’d)

Feb 9, 2016
From a client in Venezuela:

Hello, good morning and a big hug to all of you.

I am extremely grateful for the donation received a few days ago. We were able to help several Venezuelans who have an ostomy but who are happy because we were able to provide them quality of life with the generous donation sent to us.

February 8, 2016

We received a supply request from Clari Gilbert, representing the SVG [St. Vincent & the Grenadines] Retired Nurses Association. She wrote that working with ostomates is a new experience for the organization. “Someone with a new stoma was discharged home with only one bag … This person is unable to [purchase] for himself due to cost. The organization would have purchased his initial supply but there are none available on the island.” The cost is the equivalent of almost $4.50 per bag.

In addition to the original ostomate, she wrote: “I have made some preliminary inquiries and found approximately 6 persons with colostomies … It would also appear that the hospital upon discharge gives them … bags … some without flanges and barriers … Most of them say they tape the bags, which of course can be an avenue for infection from skin irritations …

I also took a picture of one of the persons today as she came to collect the supplies for her husband. She brought tears to my eyes as she mentioned how hard it is to get a few bags from the hospital. She said she got 2 last week with no clip, she had to use tape … You have helped us, the Retired Nurses, to meet a need that we did not know existed until recently.”

1/7/16
Dear F.O.W.,

My patient is a 13 years old female from Dolka (a remote area in Nepal). She studies in class one. Her village is one of the epicenters during the recent earthquakes in Nepal. Along with many destructions being done by earthquake during that time, her house was also one them due to which they suffered a lot.

She had undergone ileostomy (ileal conduit for vesicovaginal fistula) around 8 months before. Before her surgery she was unable to attend her school due to humiliation and discomfort. But after the surgery and getting the proper ileostomy bags now she has started her schools and she is doing it quite well. And she is happy to get the education now.

She is very much thankful to the F.O.W. U.S.A. She is grateful for your donations because of which she is able to lead a good life now. She is very grateful for your support to the people in such an outreach areas like her. Without this help of yours she could not have imagined such a good life which she could have only dreamt of. Thank you very much F.O.W.U.S.A.

Shanti Bajracharya, ET, Nepal
Ostomy Association

“We were able to help several Venezuelans who have an ostomy but who are happy because we were able to provide them quality of life.”
3rd Annual Fall Fundraiser a HUGE Success

It is with great pleasure that I report that our third fall fundraiser organized and run by Robin Nasatir was a huge success. Over $11,000 was raised! Robin organized the local fundraising task force of Jan Colwell, Nancy Schuller, Herb Segal (a local Chicago area volunteer), Dawn Becker (long distance support) and myself.

In addition, many volunteers attended, helping in a variety of areas.

We had many donations! A vendor who donated food from his award winning barbecue restaurant (Real Urban Barbecue in case you are ever in the Chicago area). There were several great restaurant gift certificates, many tickets to local sporting events, and items such as art and jewelry. Over $1000 in 50/50 raffle tickets were sold. Attendees paid $25 to attend, and they received a yummy meal and a piece of art to paint while perusing our auction items.

Product donations were accepted as well and many cartons of supplies were dropped off by local support groups.

Much thanks to Robin for her outstanding organizational skills and her vision to give back!

Over $11,000 raised!

Get our Newsletter e-mailed FREE at our Website!
We Get E-mails (cont’d)

Jan 13, 2016

From Ronaldo Lora of the Philippines: “The Philippines has been a recipient of a large donation from FOW-USA last 2015. The donations have been distributed to government hospitals across the country. The support group Colostomy Friends of the Philippines is one of the many groups under the National Federation of Ostomates of the Philippines, Inc., that helps poor patients through education and sharing of ostomy bags. In the picture, the officers together with members had a Christmas party celebration. Thank you to FOW-USA for the assistance given.”

Ronaldo and his group are also the Asian/Pacific winner of the Coloplast Merit Award. Their citation says: “Your application was chosen because it shows real passion and dedication for education of ostomates under the principle ‘Ostomates helping ostomates’, which truly lives up to the WOD theme ‘Many stories, one voice’. It is really impressive work.

So congratulations and well done.”

12/23/15

Mr. Denford Zvidzai, Director of Stoma Care Zimbabwe, which receives our supplies wrote us the following stories:

“A man who lives in a remote area in Zimbabwe was operated in 2011 as a result of abdomen obstructions. Before FOWs intervention, he survived with only a single disposable pouch bag borrowed from a Good Samaritan in a ward which he then improvised by piecing its base and used a clip so that it could drain; hence negatively contributing to irritation of stoma.

He could not afford to spare any penny towards the purchase of ostomy appliances as his priority was to get medication first among other things; his spouse income could not balance both his medication and family needs.

We would want to take this opportunity to thank FOW-USA and its dedicated Team in meeting people’s lives through access to Ostomy supplies as evidenced above through Stoma Care Zimbabwe.”

Denford also wrote us about a “young handicapped man who uses [crutches], living with stoma both Urostomy and colostomy due to spinal bifida and difficulties in bowel movements ....

living with stoma was one of the most dreadful encounters as the lack of ostomy supplies would often trigger pressure on his single unemployed parent and above all would make life uncomfortable .... but with the recent involvement of FOW-USA in his life with the free supply of ostomy supplies through Stoma Care Zimbabwe has relieved and restored [his] life ....

It was quite pathetic to hear [him] asking “Are all these colostomy bags for me”, a two months allocation the Organization had given him, something new in his life since he lived with stoma.

On behalf of Shepherd, Stoma Care Zimbabwe welcomes and appreciates the excellent work FOW-USA is doing in changing, restoring lives, giving hope and integrity to the less privileged in Zimbabwe.”

Stories by Denford Zvidzai, Director

“Faith is taking the first step even when you don’t see the whole staircase”

Martin Luther King
Shipping Update

Many times international shipping takes a while as each group needs to clear acceptance of the products with their government. During the next month, we will be arranging two shipments to Mongolia. One is to the Mongolia Ostomy Assoc., and the other to a new group there. Those are not included in these statistics.

In our Fiscal 2016 to date we have sent out 55 shipments weighing 9,004 pounds at a cost of $21,000 for freight. The retail value of these products was approximately $450,000. That brings our total numbers since keeping records to 319,370 lbs. of products shipped at a retail value of $15,962,633!!

Needless to say, this is where your donations go! Supplies are needed but so are your financial donations! At an average cost to ship of approximately $2.33 per pound, every dollar you send helps! Please know how grateful all of our recipients are who receive supplies from FOW-USA! Keep it coming as we can’t do this without YOU! Please go to our website www.fowusa.org and click on Shipping History, to view our shipments.

ATTENTION OSTOMY PRODUCT USERS!

Do you...

- Have opinions?
- Have access to a computer?
- Have opinions?

If YES, you qualify for the OSTOMY RESEARCH PANEL

Panelists are compensated for participation in research studies and surveys

For more information contact globalostomyresearch@gmail.com

The above research group is an independent group not affiliated with FOW-USA
We Get E-mails

April 1, 2015

Dear: FOW-USA

“This is [a story about] Nesbit who has been operated due to a growth that had developed in his colon and as a result had been inserted a stoma.

Nesbit a Family man and a bread-winner, he suffered a lot in his early years of having stoma due to stigmatization especially at work .... Being an accounts clerk at National Foods Zimbabwe, a position which does not pay much in terms of sparing his finances to acquire colostomy bags. No one wanted work with or near him due to unpleasant body odor due to limited access to ostomy supplies, and as a result the management resolved to transfer him from the main accounts department to work in one of the back offices, where later teamwork, collaboration, and socialization were jeopardized. While working from that end stress and job insecurity started to creep in as his condition would eventually lead to the termination of employment.

.... From the time FOW-USA intervened in his life through adequate constant supply of colostomy bags and other accessories free of charge his life changed drastically .... As we speak right now Nesbit is now heading an office in one of the provinces .... We Stoma Care and on behalf of the ones we serve take pride in the wonderful and marvelous work FOW-USA is doing in changing lives. THANK YOU SO MUCH

Denford Zvidzai
Stoma Care Assoc of Zimbabwe

February 17, 2016

FOW-USA supports the group Nyanza Kenya Ostomy Association (NKOAO), coordinated by Lameck Odero. One of his goals was to establish ostomy groups in Tanzania and Uganda as well. With help from those in the international ostomy community, there now exists the Resurge Children East Africa, a non-profit, which planned to found groups in those 2 countries.

From Lameck’s 2015 report: “In East Africa countries, many indigent children born with colorectal conditions are unlikely to receive the treatment they need. For some, a diagnosis is never made, for others, the diagnosis is inaccurate, but for all, the likelihood of receiving consistent care and a life-saving surgery is low. Government hospitals are often overcrowded and can only offer very limited care for these children. Waiting lists for an interventional treatment can run many months, if not years. Many children will die waiting. Some children will not even be included on a waiting list for surgery because the type of operation that they require is not available in their country. Well-intentioned bright doctors and nurses in East Africa needs help in gaining diagnostic and treatment experience as well as the necessary equipment and supplies to provide surgical, medical care now and in the future. We intend to bring a real solution to children with colorectal condition and their families by organizing and running colorectal surgical missions through partnerships with passionate, caring, committed volunteer doctors and other healthcare professionals as well as non-medical volunteers across the world who believes that we can make a difference by our actions.”

At Mr. Odero’s request, FOW-USA has sent supplies to Dr. Sister Massenga, Bugando Medical Centre, Mwanza, Tanzania. She wrote: “On behalf of our ostomates, I would like to give you my special thanks for your kindness and for receiving our request for our ostomates. Also I would like to thank all workers and facilitators of Friends of Ostomates Worldwide (FOW) USA for their contributions. Other thanks to Mr. Lameck who introduced me to you.” And then, “Today is a clinic day, I attended some of ostomates, most of them are children, adults were very few. They were more than ten patients. At the end of the day, I gave them colostomy bags, their parents were very happy. On behalf of the speechless patients, I.e kids and adults. I would like to say thank you all, including volunteers. You[r] sentence”Please let us know any time that you need more supplies’ gives us all hope. I met with urologist, the head of urology department, I informed him about the presence of urostomy bags, he was excited, he is in needy of urostomy bags, he will make use of them by distributing them to his ostomates.”

Thanks from FOW-USA to Lameck Odero and Dr. Sister Massenga for their caring actions to support ostomates in need.

On behalf of the speechless patients, I.e kids and adults. I would like to say thank you all
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.

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

Address Service Requested

www.fowusa.org

Friends of Ostomates Worldwide–USA Contribution Form

Name___________________________________________
Address________________________________________
City State Zip____________________________________
Country_________________________________________
Telephone (___)______________________________
E-mail Address ________________________________
Send Newsletter by E-Mail? Yes____ No____

Giving Level
Partner-$50____ Corporate-$300____
Sustaining -$75____ Benefactor-$1,000____
Contributing-$150____ Lifetime/Memorial- $5,000____
Supporting-$300____ Other-$$
Chapter/Group/Association $______________

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.