

# 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



Nepalese Woman Getting Supplies for Father

12/29/2012

Dear FOW-USA:

This is the picture of a 26years old lady whose father is an ostomate. Her father is 68 years old paraplegic patient with colostomy since 5 years following a fall injury. This lady in the picture comes for the colostomy bags all the way from

### Ads in Newsletter

For the first time advertisements are appearing in an FOW-USA Newsletter. We have offered advertising opportunities to ostomy-related businesses and product manufacturers on a limited basis. Only four ads will be included in any issue. This issue has two advertisers, Coloplast and Na'Scent. Edgepark Medical will have an ad in our Fall issue. Ostomy-related businesses wishing to advertise in future newsletters should e-mail:

### marilyn.zuckerman@fowusa.org

We appreciate the support of these businesses who are helping to defray the cost of printing and mailing the Newsletter. We also ask our readers to reduce costs by requesting to receive the Newsletter by e-mail. Go to our website, www.fowusa.org and sign up.

Syanja, a place far away from Kathmandu which takes a one day long walk plus a one day long bus ride to reach. She not only has to take care of her father but also her mother who is suffering from chronic kidney disease that requires regular dialysis. She has two brothers as well but they do not care about their parents at all. So she is the only one who looks after her parents. This family is financially very weak and they have no income sources. They are managing their expenses by selling the few property they have. But that would not last longer. It is very heart aching to realize how this young lady is managing to take care of both her diseased parents and her household all alone without any financial support. I am very glad that I am able to provide her with free bags to such ostomates. She is very grateful to FOW for the great help.

Shanti Bajracharya, ET, Nepal

2/4/2013

Dear FOW-USA:

These are the Pictures of the distribution of the stoma supplies donated by FOWUSA. We...appreciate your help. Roslyn Anderson,

Ostomy Support Group, Ghana



Ghana Support Group with FOW-USA Supplies

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### Newsletter Spring 2013

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Send Supplies

and Contrbutions 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's Message**

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Venice, FL

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ConvaTec (III

Sonia McDonough

Coloplast

Richard Murahata

Newsletter Editors Marilyn Zuckerman

Walt DeMoss

Madison, WI Oswego, IL

### **Newsletter Editor Change**

After five years as FOW-USA Newsletter Editor, I am handing the reins over to Shelly Miller, starting with the Fall 2013 issue. A brief bio of Shelly is on page 3. I would like to thank all of our readers and all those who have contributed articles over these years. Your support of FOW-USA is greatly appreciated. If you have suggestions for articles in future newsletters, contact us at info@fowusa.org.

Marilyn Zuckerman

Dear Friends,

This week Friends of Ostomates Worldwide USA received an email from the founder of Earthwide Surgical Foundation. The founder of this group, Dr. Camazine, sent us an appeal for ostomy pouches from a gentleman in Nigeria. Dr. Camazine and his group were contacted because this man had ostomy surgery and had no way to receive and utilize an ostomy pouching system. The picture that accompanied the email showed a piece of material wrapped around his abdomen and stoma and under the material were what looked like paper towels. As this unfortunate gentleman noted he had no way to contain what drained from the colostomy and between the gas and the odor no one was comfortable being around him and he contemplated withdrawing from life. Dr. Camazine requested and will receive the supplies to help this man as well as others manage their stoma and move on with an improved quality of life.

This is our mission at Friends of Ostomates Worldwide-USA and we are so fortunate to have outstanding volunteers to help us meet the needs of people such as the one described above. At our warehouse we have an exceptional warehouse coordinator and board member, Carol Heideman, who along with her husband Mickey receives products, and with the help of several volunteers sort and stock the supplies and send acknowledgements to the sender. When requests come into our help desk at our website at www.fowusa.org, our main shipping coordinator and board member Ruth Salinger (back up is board member Richard Cohen) works with the requestor to determine their needs and how best to meet them. Ruth then communicates with Carol at the warehouse and Carol and her volunteer team packs the pallets and makes arrangements to have these pallets picked up and shipped. Carol also receives the financial contributions at our Louisville warehouse and after she logs in the contribution, she forwards the checks to our treasurer in Texas, Rollie Sidla. Rollie prepares monthly reports on our budget as we use our budget to pay for our shipments as well as for maintenance of our warehouse. Our past treasurer and board member Al Maslov provides consultation to Rollie as well as having been instrumental in finding solutions to problems we have encountered (he is the master at problem solving!). Our newsletter editor and board member Marilyn Zuckerman has many roles in FOW-USA including the newsletter development, writing grants as well as serving on the fundraising committee (along with board members Richard Cohen and Lang Secrest). As you can see from this newsletter she works hard to provide the reader a good understanding of what we are doing and how we are working on our mission. Our past president and board member Ival Secrest is leading the charge to develop a new database to help us keep our records of donations in place and to be sure we acknowledge our donors as well as maintain a mailing list of our donors. Several of our board members are on this committee working hard to get this task accomplished.

Two of our board members, Mary Gloeckner and Judy Morey, both wound, ostomy and continence care nurses will be leaving our board later this year after several years of helping us to focus on the nursing population and how to best interact with them. Thanks Mary and Judy for your time and energy!

Continued on p. 4

### In Memorium—Lou Wray

By Ival Secrest

All non-profit organizations must have their champions. Lou Wray, along with his wife Rita, was the FOW-USA champion that saw the organization through some tough times. Lou was at the United Ostomy Association (UOA) Toronto Conference in 1986 when a special meeting was called of all the past presidents of UOA (Lou was president of UOA 1979-1980) to discuss more active involvement with Friends of the International Ostomy Association that had been established to help the less fortunate ostomates in poor countries. The result of that discussion was a decision to find a collection facility to receive, sort and ship donated supplies to those less fortunate ostomates. Lou was active from the very beginning of what we know as FOW-USA. He and Rita, along with Steve Lutz, signed the incorporation papers that launched FOW-USA as a 501 (c) (3) organization and were the primary care takers until 2001. Lou was able to secure donated warehouse space that served as the collection, sorting and shipping facility during the early and lean financial years. He and Rita unpacked the donated supplies, sorted the supplies, packed the supplies, coordinated the shipping and wrote thank you letters with a typewriter!

Additionally, Lou was on the FOW-USA Board of Directors and people who served with him were impressed with his tenacity to see that the organization fulfills its mission. Several remarked as to how he measured his words carefully to communicate his point of view convincingly without ever raising his voice. He was a true diplomat in that he could lead people with differing opinions to arrive at a common decision that was best for the organization. Lou Wray was the heart and soul of FOW-USA. Lou Wray died on October 12, 2012 at the age of 88.

# Remembering Linda Aukett

Linda Aukett passed away on March 1 after a battle with cancer. From 1992–1994, Linda served as the president of the former United Ostomy Association (UOA) and when that organization closed its doors in 2005, she and her husband Ken founded the United Ostomy Associations of America (UOAA). Since its inception, Linda served as the Advocacy Chair for the UOAA. In this role, Linda touched countless lives as a tireless advocate for ostomates on every level of government, making sure that we could pass through airport security with dignity and that our ostomy supplies will continue to be paid for by our insurance companies. Linda and her husband were product donors to FOW-USA. She will be greatly missed in the ostomy world. Linda was 69 years old.

### **New Board Members**

**Ann Favreau**— Vice President. A retired educator and published author Ann served as UOA President from 2000 – 2002. She is currently the Secretary for the Coordination Committee of the International Ostomy Association, facilitator of the Venice, FL Ostomy Support Group, member of the National Colorectal Cancer Roundtable, Membership Chair and Board member of the Venice, FL Lions Club and President of the Suncoast Writers Guild, Inc. In her spare time Ann enjoys the beach and loves to travel with her husband Ray.

**Shelly Miller**—A native Philadelphian, she transplanted to Chicago in 2002. A Penn State University graduate, Shelly worked in the field of Therapeutic Recreation for Temple University-Woodhaven Center until becoming CEO of her family's business, Miller Auto Supply, in 1978. Shelly became a "friend of Ostomates" in 1969 when her father was diagnosed with colon cancer. Shelly "joined the club" in 2008 when her severe Crohn's disease resulted in ostomy surgery. In addition to FOW-USA, Shelly serves on 2 national Boards in her field, and enjoys travel, cooking, her two French Bulldogs and golf.

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# **Shipping Report**

Between August 1, 2012 and February 18, 2013, FOW -USA shipped 9,495 pounds of ostomy supplies in 52 shipments to 36 countries. Nineteen of these shipments were sent to partners in the U.S. who forwarded the products on to the countries where they had contacts. (See related article in the next column.) Among the countries where FOW-USA directly sent supplies were Kyrgystan, Mexico, Chile, Nepal, Jamaica, Zambia, Mauritius, American Samoa, Dominican Republic, Paraguay, Zimbabwe, Jordan, Lebanon, Bolivia, Nicaragua, Ghana, Kazakhstan, Ethiopia, and St. Lucia,

The reach of FOW-USA is world-wide: Central and South America, the Caribbean, Africa, Eastern Europe and the Middle East. Through our U.S.-based shipping partners, we also sent ostomy supplies to South Asia.

Thank you to all product donors, financial contributors and volunteers who made all of this possible.

### **President's Message Continued**

Board members Lang Secrest and Ann Favreau (Vice President) along with Rollie and Marilyn are working on updating our Bylaws and Policies and Procedures to insure the continuation of our business. Our newest board members/volunteers Shelly Miller and Nicolette Zuecca have contributed to various task forces. Shelly is currently working on the webpage redesign and Nicolette has been instrumental in helping us develop our Facebook presence and designing and purchasing a new booth (that helps us talk about our mission at various meetings).

As you can see all of our board members volunteer their time to help people like the man from Nigeria get the supplies he needs because we all believe that what we are doing is extremely important. Since you get this newsletter I know you too believe that our mission is important. You can support us by sending ostomy products as well as financial donations. We are currently working on obtaining a new computer for our warehouse to help us meet the needs of people with ostomies around the world. If you can help us financially we can purchase a new computer that will be ready for our new data base. Thank you for your continued support and thank you to our Board of Directors for working so hard to help us with our mission!

Jan

# U.S. Partners in Shipping

By Ruth Salinger

Many U.S.-based groups and individuals help connect FOW-USA with ostomates in need. These groups also help reduce shipping costs as we can ship the ostomy products to U.S. locations and the group will ship them on to the country where they work. Some examples are below.

We have worked with **Dr. Rosemary B. Duda**, a doctor at Beth Israel Deaconess Medical Center and Harvard Medical School, to provide supplies to **Haiti**. One group she supports is Friends of Hôpital Albert Schweitzer Haiti, a non-profit organization that aims to support this Hospital. She also works with Partners in Health, whose goals are: "to bring the benefits of modern medical science to those most in need of them and to serve as an antidote to despair ".

Dr. Rodolfo Vargas is the President of **Friends of Rudy Nicaraguan Health.** Rudy lives in Alabama and initially was able to respond to a request from an individual in **Granada, Nicaragua.** The group has been providing mission trips for the past 12 years. We send him ostomy supplies as needed, and he takes them to the country.

June Johnson works with 3 church clinics in Ukraine. We send supplies to June's parents in Oregon, who repack the shipment into humanitarian aid boxes. These boxes are then shipped via a Christian Humanitarian Aid shipping service. They arrive in Ukraine about three months later. Each church clinic receives their own boxes and the ostomy nurse at each clinic is in charge of the distribution of the supplies.

Catholic Medical Mission Board works collaboratively to provide quality health care programs and services, without discrimination, to people in need around the world. We have sent supplies to their Long Island, New York, distribution center for such countries as El Salvador and Armenia.

The Pan-African Academy of Christian Surgeons (PAACS) is an international organization dedicated to developing quality training programs in general surgery at Christian hospitals in Africa, and to assuring a high level of professional competence among its members. We have a new client in **Gabon**, a hospital which is also a training site for PAACS. A doctor in the US will be bringing over the supplies.

Through a **US contact** for **Life in Abundance (LIA)**, we have supported children with ostomies in **Kenya**. LIA is an African-founded, faith-based community development organization.

### We Get E-Mails Continued

12/31/2012

Dear FOW-USA:

Thank you for your most recent shipment of over 200lbs of ostomy supplies! They arrived in Oregon earlier this month and the first group were shipped out this past week...The 3 church clinics I work with (are)- Zaporoshja helped 130 ostomy patients, Berdansk, 140 and I (Premorski) 15 patients.

June Johnson, Oregon for Ukraine



Ukrainian Ostomate with Nurse

1/19/2013

Dear FOW-USA,

The supplies arrived here safely and are now on the way to Honduras...Thank you again for your generosity... Gabriela Centurion, NY for **Honduras** 

Dear FOW-USA:

Friday I received two carton ostomy supplies which are sorted and packed by volunteers. I don't have word to express my gratitude and appreciation for such precious gift which are given to me & my friends. I shared these materials for a woman who are currently taking

chemotherapy treatment in Black Lion Hospital. This week I have an appointment with Aberra to give some of the materials for others he knows them.

God bless you and your work,

Teferi Tamarit, Ethiopia

3/31/2013

3/25/2013

Dear FOW-USA:

I inform you that last week, we started to hand bags and accessories to our partners...thanks to FOW-USA... Jessica Cardenas, **Chile** 



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2/25/2013

Dear FOW-USA:

I received a box of colostomy pouches recently and we are thankful for them as we have had 2 young people who needed them after bowel surgery...We are very grateful for your help.

With our sincere thanks, Sister Daisy, **Zambia** 

12/21/2012

Dear FOW-USA:

I would like to thank you so much for your support in providing Uzbekistan with ostomy supplies. We highly value the FOW -USA assistance to Uzbekistan...

With warmest regards,

Durbek Amanov, Consul General of **Uz-bekistan** in NY



### **Charitable Giving**

By Jan Colwell and Marilyn Zuckerman

At Friends of Ostomates Worldwide-USA we work very hard to provide ostomy supplies to people outside of the U.S. that have no access to any ostomy supplies. On a daily basis our help line gets 1-2 emails from people who have searched the internet for help in getting supplies for themselves or their family members. Other requests are from groups that provide health care to areas such as Nigeria, Ghana, American Samoa, India and Guatemala to name a few. We have made 52 shipments so far this fiscal year; to compare we made 54 in our entire 2012 fiscal year. The requests are increasing and the cost of shipping has also increased.

We are happy to announce that we have been the recipient of three significant corporate grants that will help us to meet the needs of people with no access to ostomy supplies outside of the U.S. Coloplast Corp. has approved a grant application from FOW-USA for pediatric ostomy supplies. This has been an urgent need of ours for quite a while.

ConvaTec Inc. and Hollister Inc. both have made financial contributions, and ConvaTec has made a product donation all of which will help us continue to ship the donated products we collect, to those in need. All three of these companies develop, test, manufacture and sell ostomy products and have demonstrated their commitment to folks with no opportunity to correctly manage their stoma. Thank you to each of these companies for walking the walk!

The International Founfation, a long-time supporter of FOW-USA has provided us with another substantial grant for this fiscal year. We appreciate the Foundation's commitment to ostomates in the developing world. Their grant will help thousands of ostomates live healthier and more fulfilling lives.

### **Journal Article**

In December 2012 the professional journal, *Wound Care Management*, published an article about FOW-USA written by Board members, Janice Colewell, President, Ruth Salinger, and Marilyn Zuckerman. Entitled "Support for Ostomy Patients: Friends of Ostomates Worldwide-USA", the article describes the needs of ostomates to successfully manage their ostomy, the difficulty ostomates in developing countries face to meet those needs, and how the work of FOW-USA and its product donors and financial contributors are helping ostomates in so many countries around the world to live successfully with an ostomy.

### **FOW-USA Board Meeting**

On Tuesday, August 6, the FOW-USA Board of Directors will convene in Jacksonville, FL for its annual in-person Board Meeting. The Board meets via Conference Call every other month during the year. At the August Meeting, which will take place just prior to the start of the United Ostomy Associations of America (UOAA) Conference (see ad next page) the Board will elect new Officers and Board Members, approve a budget for Fiscal Year 2014, review the Shipping Report, and address all other issues necessary for the successful operation of FOW-USA.

Some key FOW-USA activities this year include obtaining a new database for enhanced data storage and retreival, revising our By-Laws and Policies and Procedures to reflect changes in the organization, and developing an updated, interactive website.

Our Fundraising and Public Relations Committees have been hard at work and we have recently formed a Financial Committee to work with the Treasurer on reviewing financial transactions and other monetary matters. These committees will report at the annual meeting.

# 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 largesse. Keep sending those ostomy pouches, face plates, powders, belts, skin products, tape, and other items (but no liquids or aerosols) to our warehouse at:

FOW-USA, 4018 Bishop Lane Louisville, KY 40218

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# Seize the Opportunity to.... Live Life!

Join us for the 4<sup>th</sup> National UOAA Conference in Jacksonville FL on August 7 – 10, 2013.



Plan to arrive by Tuesday, August 6<sup>th</sup>. Registration begins at noon on Tuesday, August 6<sup>th</sup> and programming begins bright and early on Wednesday morning, August 7<sup>th</sup> and continues through Saturday the 10<sup>th</sup>.

Register on-line at <a href="http://www.ostomy.org/conference 2013.shtml">http://www.ostomy.org/conference 2013.shtml</a> Individual Registration: \$125 (does not include Sat. Banquet) Saturday Banquet: \$50 Spouse/Companion: \$75 Children 5 – 17: \$25 Children Under 5: FREE

**Reserve your room now** by calling the Hyatt Regency at 1.888.421.1442 and mention the United Ostomy Associations of America for the conference rate of \$99/night + tax

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**Spring 2013 Newsletter** 

