

# The Picture Frame

A publication of the  
Ostomy Association of Greater Orlando

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Affiliated Support Group

2018  
Happy New Year!



[www.ostomyassociationofgreaterorlando.com](http://www.ostomyassociationofgreaterorlando.com)

## MEETING ANNOUNCEMENTS

### Saturday, January 20, 2018 @ 10:30 AM

Please welcome **Kevin Hershey**  
from the B-Braun Corporation.  
He will show us some new products.



### Saturday, February 17, 2018 @ 10:30 AM

#### Round Table Discussion:

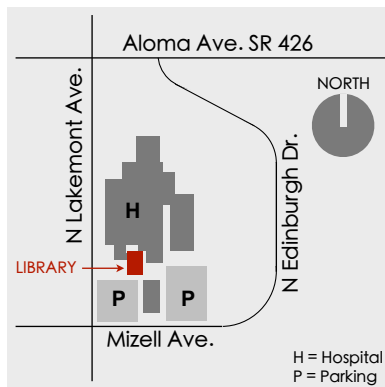
This is a great opportunity for new and experienced  
ostomates to share stories and information.

#### MEETING INFORMATION:

Our fellowship meetings offer an exchange of valuable information offered by our speakers, members, and guests. All are welcome, especially supporting family and friends. Coffee is provided and donated treats are always welcome.

#### MEETING LOCATION:

Winter Park Memorial Hospital Library, 200 N Lakemont Ave. The Library is adjacent to the parking lot and has large black letters "LIBRARY" above the entrance.



If you are not a member, please join us. Our low annual dues of \$20.00 are not mandatory, but allow us to continue our programs to help others. Donations to the Ostomy Association of Greater Orlando, Inc. are tax deductible.

#### FOR MEMBERSHIP INFORMATION PLEASE CONTACT

**Shelley Dittmer 407.929.3668**  
**Evelyn Vihlen 407-862-6567**

If you are not interested in receiving the Newsletter please call or email us at [ostomyorlando@aol.com](mailto:ostomyorlando@aol.com)

#### DO YOU HAVE INTERNET ACCESS?

If you have internet access you can help reduce our costs by electing to receive the newsletter via email. Please call Shelley at 407.929.3668 or email us at [ostomyorlando@aol.com](mailto:ostomyorlando@aol.com). Thank You.

#### PLEASE DONATE YOUR UNUSED OSTOMY SUPPLIES

If you have unused supplies please bring them to our meetings or call Evelyn Vihlen at 407.862.6567 or Jack Vreeland at 407.415.8855. Donated supplies are given free of charge to those without insurance.

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### IT'S THAT TIME OF THE YEAR AGAIN

The Ostomy Association of Greater Orlando cannot continue its programs without your support. Through your membership and contributions we are able to support those facing ostomy surgery and those with ostomies through our meetings, Mentor/Visitation Program, Gift Room, and Youth Rally sponsorship.

**Membership Application and Renewal Form** on Page 2.

**Thank You for your support.**



#### Premier Online Version

Get instant access to *The Phoenix* magazine by ordering the Premier Online Version. Read the magazine through any web browser on your computer, iPad, or any other device where you can browse the Internet. Annual Premier Online Edition subscription is \$19.95. Annual print subscription is \$29.95. See ad and on Page 8.

# What's going on at OAGO ?

## PRESIDENT'S MESSAGE

HAPPY NEW YEAR EVERYONE!

First I would like to thank some of our members for helping with jobs such as the "Gift Room" collections. Both Jack Vreeland and Terry Sniderman have done a great job of connecting with folks that wanted to donate unneeded supplies.

Of course **Evelyn** is always there to mentor new ostomates and keep supplies.

Also, Neal Mengel is helping with membership renewals. **HAVE YOU RENEWED YOUR MEMBERSHIP YET?** We need to hear from you! Thanks Neal!

Be sure to join us for **our January 20<sup>th</sup> meeting.** We have **Kevin Hershey** from B-Braun coming to show us a new product that they are offering. I have seen it at the UOAA conference, but never was able to try it.

I also want to again thank our November speaker, Ryan Rice from Planet Fitness. Great job Ryan.

Lastly I have some good and bad news to share with you.

First of all, our Web Master, Bob Woodrow is recovering from a 41 day stay in hospital and rehab after hip replacement and femur surgery! So glad you are doing better Bob! When we said "Break a Leg" we really did not mean it!

And sadly we have lost a longtime member, Vanra Decker. She was our Newsletter editor for several years, and an all-around good friend. We will miss Vanra and her fun PartyLite parties! Please keep Chuck, her husband, and family in your thoughts.

See you on January 20<sup>th</sup>- **Shelley**

Our member Shabbir Adam, mentioned in the Press Release below, is a compassionate individual and philanthropist whose mission is to help fellow ostomates by shipping unused ostomy supplies to cancer patients in Trinidad, Jamaica, Haiti, Guyana, and most recently Barbados. He has also been involved with projects in India including the construction of a new orphanage building and has built hundreds of wells around the country.

If you wish to contribute to his mission, please call Shabbir at 407.929.7333 or email him at [shabbiradam@hotmail.com](mailto:shabbiradam@hotmail.com).



## Barbados Muslim Association

### MEDIA RELEASE

The Barbados Muslim Association is pleased to facilitate this donation of Ostomy Supplies to the Barbados Cancer Society.

These supplies were obtained through the efforts of Mr. Shabbir Adam, a member of the Islamic faith in Florida, USA from The Ostomy Association of Greater Orlando Inc. The Ostomy Association of Greater Orlando is a not for profit corporation in the State of Florida and an affiliate of the United Ostomy Associations of America.

Through their generous and kind donation facilitated by Mr. Adam the Barbados Muslim Association is extremely happy to facilitate today's presentation of the Ostomy supplies to the Barbados Cancer Society.

We thank the Barbados Cancer Society for their continued work in helping persons in need of support and care and are happy for this opportunity to assist in some way towards their work.

The Barbados Muslim Association on behalf of the Muslim community of Barbados continues its efforts in giving back to the Barbadian society in a meaningful way.

For more information please contact Dr. Abdul Mohamed, President at 2309437 or by email at [info@islambarbados.com](mailto:info@islambarbados.com)

## MEMBERSHIP APPLICATION & RENEWAL FORM

Membership in the Ostomy Association of Greater Orlando, Inc. is open to persons with all types of intestinal and urinary diversions, as well as supporting family, friends, organizations, and businesses. **This form may be used for both new memberships and renewals.** Renewals are due on January 1 of each year. **Thank you for your support.**

**PLEASE PRINT** Name: \_\_\_\_\_ Date: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_

State: \_\_\_\_\_ Zip: \_\_\_\_\_ Phone: \_\_\_\_\_ Alternate Phone: \_\_\_\_\_

Email Address: \_\_\_\_\_ Date of Birth (optional): \_\_\_\_\_

**Type of diversion(s)** - Circle all that apply or check None. Information will be kept CONFIDENTIAL.

Ileostomy Colostomy Urostomy Ileoanal Reservoir/J-Pouch Continent Ostomy Other: \_\_\_\_\_ Date of Surgery: \_\_\_\_\_ None: \_\_\_\_\_

**Dues and Donations** (Donations are tax deductible)

\$20.00 Enclosed are my dues for membership in the Ostomy Association of Greater Orlando, Inc.

\_\_\_\_\_ Enclosed is an additional donation to support all of our ongoing programs.

Please make checks payable to the **OAGO**. Bring this form and payment to our next meeting, or mail to:

**Patrick Rodgers, Treasurer**  
307 E Citrus Street  
Altamonte Springs, FL 32701

***"I struggle with my laziness. I'm like, "Should I sit down and do nothing or lie down and do nothing?" Jim Gaffigan***

## 6 Organizations Dedicated To Providing Support And Education For Urostomates

*These groups prove that urostomy awareness does make a difference.*

*by Rachel Jury, November 22, 2017, featured on [OstomyConnection.com](http://OstomyConnection.com)*

November is **National Bladder Health Month** and we'd like to help connect ostomates in our community to important information about bladder conditions and resources for education and support. There's definitely value in knowing the right organizations, and finding support is something every person with an urostomy should consider. Here are six excellent non-profit organizations that urostomates can turn to for help.

### 1. United Ostomy Associations of America

The **United Ostomy Associations of America, Inc.** (UOAA) is a non-profit organization that supports, empowers, and advocates for people who have, or who will have an ostomy or continent diversion surgery. Whether you're looking to join one of their 300+ Affiliated Support Groups (ASG) across the United States, or seeking answers online through their community forum, UOAA has helpful resources and guides available for people with urinary diversions. Membership to UOAA is open to anyone in the United States through an ASG, or individually. The Phoenix magazine is published quarterly and is available in print or digital versions.

Website: [ostomy.org](http://ostomy.org)

### 2. Urostomy Association

The **Urostomy Association** (UA) is a registered national Charity in the United Kingdom that was founded by a group of people at the Christie Hospital in 1971 to assist people who are about to undergo or who has already had surgery resulting in a urostomy, continent urinary pouch or a neo-bladder. To provide additional support and face-to-face contact for its 2,500 members, the UA has several local branches which hold meetings two or three times a year. Those who are not residents of the UK can join their Postal Branch membership which is available worldwide. The UA Journal is published three times a year and is available to members of the Association.

Website: [urostomyassociation.org.uk](http://urostomyassociation.org.uk)

### 3. Bladder Cancer Advocacy Network

The **Bladder Cancer Advocacy Network** (BCAN) was founded in 2005 and is the only national advocacy organization devoted to advancing bladder cancer research and supporting those impacted by the disease. Their video series, "The New Normal: Living with a Urinary Diversion" profiles eight bladder cancer survivor stories to let others know about living well with a urinary diversion. BCAN has eight State chapter groups and numerous in-person groups throughout the United States and Canada. Registration for the 2018 Walk to End Bladder Cancer began in October, visit their website to find an event near you.

Website: [bcan.org](http://bcan.org)

### 4. Fight Bladder Cancer

**Fight Bladder Cancer** is the only UK-based bladder cancer charity founded and run by bladder cancer survivors and their families. They provide support to those living in the United Kingdom affected by bladder cancer which, of course, includes those who have urostomies. Their support services include an online confidential forum which has about 3,500 members, and a nationwide 1-to-1 peer support service called Bladder Buddies. FIGHT Clubs are local support groups which we are opening up across the country as networked clubs. They also publish FIGHT magazine, which often includes inspirational patient stories of those with urostomies and neobladders.

Website: [fightbladdercancer.co.uk](http://fightbladdercancer.co.uk)

### 5. Association for the Bladder Exstrophy Community

The **Association for the Bladder Exstrophy Community** (A-BE-C) is an international support network of individuals with bladder exstrophy, including classic exstrophy, cloacal exstrophy, and epispadias. They assist patients and families living with bladder exstrophy by making education, support, webinars, and resources available to those living with bladder exstrophy. Courage To Shine is the patient awards program of the Association for the Bladder Exstrophy Community and was founded to acknowledge individuals who have overcome congenital genitourinary birth defects or major urological surgeries and transformed that adversity into triumph.

Website: [bladderexstrophy.com](http://bladderexstrophy.com)

### 6. Mitrofanoff Support

**Mitrofanoff Support** was founded in early 2010 by Kyla Rogers and in February, 2012 they officially became a Registered Charity in England and Wales. For those not familiar, mitrofanoff is a surgical procedure in which the appendix is used to create a conduit between the skin surface and the urinary bladder. This charity provides emotional support, reassurance, information and networking online and at two Patient Education Days events every year. They cannot accept members outside of England and Wales due to Charity Commission laws, however everyone is welcome to join their Facebook group.

No matter where you live in the world, these organizations are a fantastic way to connect with fellow ostomates. As a young urostomate and ileostomate, my hope is that you'll become more involved in urostomy awareness so we can all come together to share our experiences and empower each other.

Website: [mitrofanoffsupport.org.uk](http://mitrofanoffsupport.org.uk)

Source: [OstomyConnection.com](http://OstomyConnection.com), A Hub for Ostomates. Reprinted with permission.

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*My bed is a magical place where I suddenly remember everything I forgot to do.*

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Happy Birthday  
to those born in  
January  
and February!!!



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## Colostomy Irrigation

By Mary Lou Boyer, BSEd, RN, CWOCN Lifetime Achievement Award Winner, Cleveland Clinic

You may have seen or heard the term "irrigation" used in conjunction with ostomy care. There are several different ways this word is used and it can have very different meanings.

Some people with ostomies say that they "irrigate" their pouch or appliance each time they empty. In these cases, it is a matter of adding water to help loosen thick or formed stool to assist in emptying the thick stool from the pouch. Or it can mean rinsing out the pouch with water until the pouch appears clean. In other cases the term "irrigation" is used when referring to a procedure that some people with descending or sigmoid colostomies may use to cleanse or regulate the bowel by instilling water into the large intestine through the stoma. This is called "colostomy irrigation".

Over the many years that colostomy irrigation has been an option in colostomy care, there has been some debate about whether or not an individual should irrigate. In making that decision the following are questions that should be considered: what is colostomy irrigation? Who is an appropriate candidate? Why is it done? When is it done? And how is it done? This article is an attempt to answer these questions.

Colostomy irrigation is a method of assisting the bowels to move at a certain time. The procedure itself is similar to an enema, however it is done with specialized equipment to instill warm water through the colostomy stoma. A large water bag with tubing that has a cone-shaped tip is inserted into the opening of the stoma. The cone-shaped catheter tip allows the water to flow into the colon while preventing the water from leaking back out. As the colon fills with water, it distends. This distention stimulates colon peristalsis and mass contractions that lead to stool evacuation.

Colostomy irrigation is an option only for people who have a descending or sigmoid colostomy. In the normal bowel, the function of the colon is to absorb water from the waste material and to store it for a normal bowel movement. In most cases this can be as often as once or twice a day, or less frequent, such as every other day. There must be enough of the large intestine to absorb and store. The anal sphincter muscle is used to control the bowel movement until a convenient time. When most of the colon is still in place, the bowel can generally return to the usual pattern the person had prior to surgery. With a colostomy there is no longer a sphincter muscle to hold the stool in until a convenient time to go to the bathroom. Stool will flow into the pouch with no control over the timing. This loss of control that comes along with having a stoma can result in stool flow into the pouch at inconvenient or embarrassing times. Gas can also be an issue.

Colostomy Irrigation is used to empty the colon for any of the following reasons.

- \* To regulate the bowel
- \* Clean out the bowel for testing procedures, including colonoscopy
- \* To stimulate bowel function for constipation or if the colon is very slow to wake up after the colostomy surgery

When colostomy irrigation is used to help stimulate bowel function after intestinal surgery, only a small amount of warm water is instilled. This is done after the normal waiting time for stool flow has passed. Anesthesia, pain medications and inactivity after surgery all contribute to slowing the bowel down and delaying return of normal peristalsis needed to have bowel function. Colostomy irrigation can be used as a possible method for cleansing the bowel in preparation for colonoscopy, laboratory testing, x-rays, barium enema and CT scans, as well as any other testing that requires the bowel to be empty for clear visualization by the physician. Cleaning out the bowel for testing has shifted more toward oral preparations with the advancements of laxative-type bowel cleansing medications. However, irrigation is still an option, especially for those patients with certain health issues or who cannot tolerate oral preparations.

When colostomy irrigation is used to regulate the bowel, the procedure is done daily. If the normal pre-surgery bowel pattern was less frequent than daily, the procedure can be done every other day. It may take a couple of weeks to "train" the bowel to completely empty at the time of irrigation. The desired result is to move all of the stool out with irrigation and have no spillage of stool into the pouch between irrigations. The best results are obtained by doing the procedure at the same time every day in order to "train" the bowel for evacuating on a regular basis at a convenient time. For some people it is most convenient to perform irrigation in the morning and for others the best time is in the evening when they are not rushing off to work or other daily activities. It is up to the patient's personal preference.

**Continued on Page 5**



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407-929-3668

[shelleydittmer@nascent4u.com](mailto:shelleydittmer@nascent4u.com)

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### Colostomy Irrigation, continued from Page 4

If the procedure works well, the person with a descending or sigmoid colostomy can count on regular evacuations and the need for a pouch is minimized. The patient who irrigates successfully may wear only a small stoma cap or gauze square over the stoma between irrigations. Some wear a small pouch just for security.

Colostomy irrigation is not always appropriate or even desirable for every person who has a sigmoid or descending colostomy. The person's age, physical and mental ability to learn and perform the procedure, the disease process, and whether or not the ostomy is temporary or permanent are all factors that need to be considered.

Irrigation is NOT recommended for people with any of the following conditions:

- \* Stomal prolapse - Irrigating can increase the risk for further prolapse
- \* Parastomal hernia - Hernias change the contour and angle of the intestine so there is increased risk for bowel perforation and poor evacuation results
- \* Children or young adults - In younger people, routine irrigation may create bowel dependency. In other words the bowel may not be able to function normally without irrigation if the routine is started at an early age.
- \* Pelvic or abdominal radiation - Radiation can cause damage to the tissue of the intestine. Anyone with abdominal radiation has an extreme risk of bowel perforation, so it is important not to add any extra pressure to the fragile tissue.
- \* Diverticulitis - Because the bowel tissue is already compromised from this disease process, there is a much higher risk of bowel perforation.
- \* Patients with limited manual dexterity
- \* Patients with poor learning ability
- \* Persons who had poor bowel regularity before surgery will likely have poor results from irrigation
- \* Extremely ill or terminally ill patients - Routine irrigation is usually not recommended for these patients because of the time and energy required for the procedure

When colostomy irrigation is being considered, it is important to first determine if the individual is a good candidate. In other words, are there any of the above risk factors? If not, then consider the advantages and disadvantages of the procedure, keeping in mind that the procedure, from start to finish, can take up to 45 minutes or even an hour.

The chief advantage is regaining control over fecal elimination. If irrigation is successful, it can reduce the number of pouches used. It may even be possible to choose not to wear a pouch and only use a small protective covering. Successful management of the colostomy with irrigation may assist in the psychosocial adjustment to the colostomy. Disadvantages include the time required for the procedure and not all patients can achieve complete control with irrigation. If elimination patterns change or become unpredictable, the patient may not be free of bowel movements between irrigations.

Research shows that colostomy irrigation was first used in the 1920s and through the years it was taught routinely to patients with a descending colon or sigmoid colostomy. Among the chief reasons for teaching this routinely was the lack of quality pouches to contain thick or formed stool as they were bulky and did not adhere well to the skin. As pouching systems improved with more advanced technology, Colostomy irrigation as a widely used "routine" procedure lessened and began to be used more for personal preference, or on a need to know basis.

Regulation of the colostomy using irrigation is a personal matter. Life style and occupation often lead in making the choice. The final decision of whether to use this method or not should be made by the patient with proper guidance from health care professionals. Only those patients who meet the established criteria for irrigation should proceed with using this method of bowel management.

#### Irrigation Procedure:

1. Gather equipment
2. Fill irrigation container with 1 liter warm water. Run some water through the tubing to remove air
3. Hang container at shoulder height with patient sitting on toilet or chair near toilet.
4. Remove old pouch or covering from stoma
5. Attach irrigation sleeve over stoma
6. Lubricate cone irrigator and gently insert into stoma. Hold cone gently but firmly against stoma to prevent back-flow of water.
7. Open clamp and allow water to flow. If cramping occurs, shut off water flow, keeping cone in place until cramp subsides, then continue.
8. After water has been instilled, gently withdraw cone and close top of irrigation sleeve.
9. Allow 15-20 minutes for most of return, dry and clamp bottom of sleeve. Patient may proceed with other activities.
10. Leave sleeve in place for approximately 20 minutes
11. When evacuation is complete, remove sleeve, clean peristomal skin and apply pouch or protective covering.
12. Wash equipment.

## **OUT PATIENT OSTOMY CLINICS IN CENTRAL FLORIDA**

The Ostomy Association of Greater Orlando frequently receives calls from individuals who are dealing with skin and product issues. Below is information on outpatient ostomy clinics.

### **Orlando Health Wound Healing Center**

#### **Services Provided:**

Comprehensive ostomy and fistula care are offered, as well as pre-operative stoma site marking and teaching. Donations of ostomy supplies are welcomed as we see many indigent and homeless individuals.

#### **Location:**

Orlando Regional Medical Center  
Orlando Wound Healing Center - Ostomy Clinic  
55 West Gore Street, Annex Building, First Floor  
Orlando FL 32806

**Location Note:** The Orlando Wound Healing Center is located just west of Main Lane at the intersection of West Gore Street and Kuhl Avenues. The entrance door to clinic is under the drive through canopy.

**Ostomy Clinic Phone:** 321-841-5469 FAX: 321-841-7470

**Requirements:** Appointment and doctor's script/order required, along with demographic sheet, last progress note.

**Insurance:** Most insurances accepted. Medicare and secondary insurance accepted.

#### **Principal Staff:**

Sally Matson, RN BSN MS CWOCN.  
Karen Durigan, Nursing Operations Manager.

### **Central Florida Wound and Skin Consultants**

#### **Services Provided:**

- NP-C/WOCN specialists provides ostomy evaluation and refitting to homebound or ALF patients in their homes.
- We are a **mobile** ostomy, wound and lymphedema medical practice caring for Medicare patients only.
- Our medical practice also specializes in customized hernia support options.
- Preoperative education and stoma marking.
- Postoperative education on stoma management including pouching system selection and education on self-care.
- Assistance with appliance fittings, pouching system failures, peristomal skin loss, ulcers, and rashes.
- Management of complex, high output fistulas.
- Services also offered at Assisted Living Facilities in Orange and Seminole County.

**Phone and Fax:** 407-359-6426

**Requirements:** No doctor's script/order required.

**Insurance:** We are Medicare providers and do not accept HMO or PPOs. We bill direct to Medicare and secondary insurances. Self pay rates: \$175.00 for initial visit, \$75.00 for additional visits. We accept payment by cash or check.

#### **Principal Staff:**

Tabassum Merchant MS, WOCN, MSN, NP-C  
Debbie Moulavi CWON, MSN, NP-C  
Collaborating Physician: Rita Laracuente, MD

#### **About Tabassum Merchant and Debbie Moulavi:**

Board certified nurse practitioners with a speciality in wound and skin disorders. Additional training through WOCN Program at Emory University. We are also known as NP/ET/WOCN specialist. Able to write prescriptions and provide a medical service for the treatment of ostomy related disorders.

## **Out Patient Ostomy Clinics in Central Florida continued**

### **DAYTONA**

#### **Florida Hospital Memorial Medical Center**

#### **Location:**

Center for Wound Healing and Hyperbaric Medicine  
Florida Hospital Memorial Medical Center  
Center for Wound Healing  
301 Memorial Medical Parkway  
Daytona Beach, FL 32117

**Ostomy Clinic Phone:** 386-231-3615

Appointment and doctor's script/order required.

**Insurance:** Most insurances accepted. This facility is a Medicare assigned provider and accepts Medicare Secondary insurances.

### **PALM BAY**

#### **Health First Outpatient Wound Center/Ostomy Clinic**

Appointments on Wednesday's only.

To schedule an appointment: 321-434-6100.

Appointment and doctor's script/order required.

### **OAGO GIFT ROOM**

The Gift Room is stocked with donated unused ostomy supplies that we collect and provide, free of charge, to fellow ostomates who are uninsured or underinsured. This service is run solely by the **Ostomy Association of Greater Orlando, Inc.** on a volunteer basis under Gift Room Director Evelyn Vihlen. For information call 407-862-6567.

### **OSTO GROUP**

This not-for-profit organization provides free ostomy supplies to those without insurance. Your only cost is shipping and handling. Call 877-678-6690 or visit their website at [www.ostogroup.org](http://www.ostogroup.org).

### **FRIENDS OF OSTOMATES WORLDWIDE - USA**

*UOAA Update November 2014*

The modern ostomy supplies we take for granted in the U.S. and other developed countries may be unavailable or too costly in many areas around the world. People resort to plastic bags, rags, and duct tape, resulting in poor skin, odor, no jobs, and no school. Since 1968, the Friends of Ostomates Worldwide-USA (FOW-USA) has collected new supplies from U.S. individuals and groups and sent them overseas where needed. From Afghanistan and Cameroon to Zambia and Zimbabwe, to over 70 countries, our shipments have made a difference. You can too, with supplies and financial donations: FOW-USA, 4018 Bishop Lane, Louisville, KY 40218. Phone: 502-909-6669 Website: [www.fowusa.org](http://www.fowusa.org)

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*To report abuse, neglect, or exploitation call 1-800-962-2873*

## Disaster Preparedness

By R.S. Elvey courtesy of *The Phoenix*

### Natural disasters are on the rise - plan ahead to be prepared

If you think there are more natural disasters than when you were a child, you are correct. The years 1980 to 2009 saw an increase in climate-related natural disasters by 80 percent. The United States now ranks second behind China with the most natural disasters according to [www.statista.com](http://www.statista.com).

The majority of natural disasters in the United States are climate-related as opposed to geophysical, such as earthquakes and tsunamis. In 2016 alone, there were around 971 tornadoes, mostly from northern Texas through Oklahoma, Kansas and Nebraska. Additionally, there were 19 separate floods, 68,000 wildfires, 4 major hurricanes and 15 tropical storms.

### Plan to Be Prepared

For an ostomate living in areas affected by natural disasters, it is important to plan for these events. Whether you shelter in place or evacuate, the Federal Emergency Management Agency (FEMA), says, "If you take medicine or use medical supplies on a daily basis, be sure you have what you need on hand to make it on your own for at least a week."

Bill Kuhn, a urostomate, leads an ostomy support group in Metairie, LA. He lived through Hurricane Katrina and advises, "Have an emergency kit with enough ostomy supplies for at least seven to fifteen days." Bill further urges to know your primary evacuation route. Should that be unavailable, know an alternate route. Additionally, you should find out the final destination for both primary and alternate evacuation routes. For each final destination you should write down the contact information for the local ostomy support group in that area. A directory of U. S. support groups can be found at [www.ostomy.org](http://www.ostomy.org). Finally, whenever possible notify friends and relatives of your evacuation.

### General Medical Information

Both FEMA and Bill divide disaster planning into two areas: general medical information and emergency medical supplies kit. General medical information should include:

1. Reference numbers for all your ostomy supplies and your supplier's contact information.
2. A complete health history on paper and a thumb drive to include your doctor's contact information and hospital affiliation, prescription drugs, medical conditions and allergies.
3. An undated prescription for ostomy supplies.
4. Written directions on how to change your pouching system in case you are physically impaired.
5. Medical ID bracelet, necklace or written information about your physical disabilities.
6. Contact numbers of relatives and friends.

### Emergency Ostomy Supplies

Once your medical information is assembled, it is time to put together your emergency ostomy supplies kit. You should plan to have at least seven to fifteen days' worth of supplies. Ostomy care is very individualized, so use this guideline as a "baseline" and adjust as necessary.

1. Pouching systems for 7-15 days.
2. Towel, washcloth or wipes.
3. Pair of scissors.
4. Bags to dispose of used supplies.
5. Hand sanitizer.

*Optional:*

6. Clothing clips.
7. Skin cleanser with no oils or lotion.
8. Adhesive remover wipes.
9. Skin prep wipes.
10. Ostomy powder.

Assemble the supplies in a waterproof and dust proof container. Depending on your lifestyle, you could use a waterproof backpack like the Driftsun Dry Gear Backpack available from [www.driftsun.com](http://www.driftsun.com) or any other weather proof bags from retailers such as Walmart and the Container Store, or a plastic storage bin. But always remember to store all your records, supplies, phones and laptops in individual water proof bags like Pelican Pouches or zip lock bags.

### Proper Disposal

Finally, as ostomates we must plan an emergency method to empty our pouches when traditional toilets are not available. For urinary disposal, the portable male or female urinal with locking lid should be part of your emergency kit. For solid waste disposal there are two options - with a bucket or without a bucket. If you have a bucket then the TravelJohn provides a leak proof and odorless way to empty an ostomy pouch, [www.traveljohn.com](http://www.traveljohn.com). The TravelJohn is a biodegradable bag within a bag that fits over a bucket or stand and then folds over and seals for disposal. Each bag contains crystals that turn waste into an odorless gel. Sold in packages of three, each TravelJohn also contains antiseptic hand wipes and toilet paper.

When you do not have a bucket and must empty your pouch, then consider a Biffy Bag available at [www.biffybag.com](http://www.biffybag.com). This personal disposable toilet system fits in the palm of your hand and does not need a bucket. The green Biffy Bag simply ties around your waist. When done simply tie up the bag and stuff in the attached foil disposal bag. Each Biffy Bag contains a liquid solidifier, decay starter, odor eliminator, toilet paper and oversized hand wipe. The green Biffy Bag is biodegradable. Biffy Bags are sold in quantities of 3, 10 and 25.

The most critical way to survive and deal with a natural disaster is to plan ahead. But recovering from a natural disaster will always involve some impromptu decisions and reacting to the realities on the ground as they happen. We can't always know ahead of time how events will play out.

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***"Never let yesterday use up too much of today."*** Will Rogers

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The Phoenix is the leading national magazine for ostomates, their families and caregivers. Subscriptions directly fund the nonprofit United Ostomy Assoc. of America – the only national organization providing vital information, resources, support and advocacy for ostomates.

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**ABOUT US:** The Ostomy Association of Greater Orlando, Inc. is an IRS 501(c)(3) tax-exempt charitable corporation in the State of Florida with “umbrella” status under our parent company, United Ostomy Associations of America, Inc. We are an all volunteer support group dedicated to assisting people who have or will have intestinal or urinary tract diversions by providing emotional support, family support, educational services, advocacy, and promoting the services of this organization to the public and professional communities.

### IMPORTANT NOTICE

Articles and information printed in this newsletter are not necessarily endorsed by the Ostomy Association of Greater Orlando, Inc. and may not be applicable to everyone. Please consult your doctor or WOC Nurse for medical advice that best suits your specific situation.

### POPULAR OSTOMY RELATED WEBSITES

#### [www.ostomy.org](http://www.ostomy.org)

United Ostomy Associations of America (800-826-0826) is an association of Affiliated Support Groups. UOAA serves people with ostomies and other intestinal and urinary diversions through its affiliated support groups. UOAA is a member of the International Ostomy Association. Their website has a large discussion board with over 10,000 topics posted by ostomates. Individuals can join UOAA simply by joining the **Ostomy Association of Greater Orlando**.

#### [www.ostomyassociationofgreaterorlando.com](http://www.ostomyassociationofgreaterorlando.com)

Our website contains information on our support group including meeting calendar, directions to our meetings, new member application, useful links, list of ostomy suppliers, helpful articles, and much more.

#### [ostomyconnection.com](http://ostomyconnection.com)

OstomyConnection is an online resource to find the very best support, events, products, and advice for the ostomy community. We help ostomates stay connected to the stories and topics that affect our daily lives.

#### [www.Ostomy.Inspire.com](http://www.Ostomy.Inspire.com)

The Inspire Ostomy Support Group is a great way to meet and connect with a community of people who understand what you're going through. ConvaTec partnered with Inspire to create this social network where people with ostomies can gain emotional and informational support.

#### [www.c3life.com](http://www.c3life.com)

A website dedicated to helping people with ostomies live their lives to the fullest. Supported by Hollister Inc., c3life.com is part of Hollister's mission to help make life more rewarding and dignified for those with ostomies.

#### [www.meetanostomate.com](http://www.meetanostomate.com)

Provides a free collection of real-life tips and tricks from ostomates.

#### [www.ostomyland.com](http://www.ostomyland.com)

Has provided ostomy support since 1998, including interactive support, chat, blogs, lifestyle guidance, lists of ostomy product manufacturers, and ostomy undergarment and accessory manufacturers.

#### <http://uncoverostomy.org>

Uncover Ostomy is an entirely online awareness campaign sparking positive conversation about ostomies. Spokesperson and Founder, Jessica Grossman shares positive stories, thought provoking images, and ways for you to spark this conversation.

#### <http://weneedideas.ca>

IDEAS, Intestinal Disease Education and Awareness Society.

#### [www.google.com](http://www.google.com)

Type “youtube” in the google search box, then type “ostomy” in the youtube search box. All the audio/visual guidance you could ever want.

#### <http://www.veganostomy.ca/>

Find the latest ostomy product reviews, friendly how-to's and support. Including topics about Crohn's, Ulcerative Colitis, and living a vegan lifestyle.

### THE OSTOMATES PRAYER

Oh Lord, as we have been reborn, let us multiply our good fortune and share it with those ostomates who do not know how good the life you have given us can be. Let us vow in the years ahead to renew the work of our group, as you have renewed our lives. We thank you for our lives, for the mutual support of each other, and for the chance you have given us to help others. Amen. *Via the Clermont County Chapter, the Batavia OH Chapter, and Indianapolis IN Chapter*