

## Welcome!

The Cedar Rapids / Iowa City Area Ostomy Support Group is dedicated to providing information, advocacy and service to our members, their caregivers, and to the intestinal and urinary diversion community at large.

## Our local chapter

We meet regularly to share experiences, provide mutual support and learn about the latest products and information for ostomy, urostomy and intestinal diversions.

Meetings are held at area hospitals, and involve informal round-table discussions on topics of interest, new product demonstrations, occasional guest speakers, and a question and answer session with one of the local WOC nurses. Families and friends of ostomy and intestinal diversion patients are always welcome to attend.

**For more information about the local chapter,** contact us at 319-530-6749, at [www.iowaostomy.org](http://www.iowaostomy.org), or [find us](#) on Facebook.



## The U.O.A.A.

The United Ostomy Associations of America is a 501(c)(3) non-profit organization. The UOAA serves to unify and strengthen ostomy support groups in America.

UOAA services include: Advocacy • Non-profit Status • Conferences • The Phoenix magazine • Toll-free Help and Referral Line • Special Interest Groups • Ostomy Community Liaison

**For more information,** contact the UOAA at 800-826-0826, or at [www.ostomy.org](http://www.ostomy.org).

*“Seize the Opportunity”*

## From our Coordinator...

We had a wonderful time at our annual Holiday Party and meeting at Ryan's Buffet in December. Many thanks to Wilma Gilmore, Jim Kee, Bonnie Lorenzen and everyone else who helped make the day so much fun. Our panel of esteemed judges voted on the best decorated “ostomy stocking” and once again, everyone was a winner - imagine that!



Here are a few photos from the party



Our next meeting is Thursday, February 19th at 6:30 pm at Mercy Medical Center in Cedar Rapids. See details on page 4. We are planning a “movie night” and will have several short videos which are ostomy related.

*Continued on page 2*

## ***This and That... ostomy news you can use!***

We'll also share samples of a new product called Ostomy Pockets, and vote on some minor changes to the UOAA Constitution.

Ostomy Education Day, sponsored by the Iowa WOCNs, is Saturday, April 11th at Mercy Medical Center in Des Moines. I encourage all to attend this very worthwhile event.


Finally, Gina Carlile and Bonnie Lorenzen have been working on our new Facebook page. Gina has made it a 'closed group', which means any posts you make on that page are visible only to group members. Our goal is to reach ostomates who can't attend support group meetings, but who are active on social media. We'd like our Facebook page to become the place to go to, for ostomy information, discussion, new products and more, for ostomates in Eastern Iowa. More specific information on the new Facebook page will be sent soon in a separate email.

*Carol Haack*

### Get Ostomy Answers!

The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more.

Subscriptions directly fund the nonprofit United Ostomy Associations of America – the only national organization providing vital information, resources, support and advocacy for ostomates.



**The Phoenix**

☐ One-year subscription \$29.95    ☐ Two-years for \$49.95  
Payable to: The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690

www.phoenixuoa.org  
or call 800-826-0826

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Save the date:

## **OSTOMY EDUCATION DAY**

**SATURDAY, APRIL 11<sup>TH</sup> 2015**  
**MERCY MEDICAL CENTER**  
**DES MOINES, IA**

Please join us for this free annual event designed to offer ongoing support and education to people living with ostomies and their families/caregivers.

More information available early 2015. Please email [iowaostomyday@gmail.com](mailto:iowaostomyday@gmail.com) for details.

Sponsored by the Iowa Affiliate of the Wound Ostomy and Continence Nurses Society.

*Make your plans now to attend the Ostomy Education Day, sponsored by the Iowa WOCNs.*

*This is always a great event and we have fun and learn a lot.*

*We are trying to get specific details on how to register.*

*We will keep you informed as more information becomes available.*

## **Message from the UOAA:**

It's time for UOAA National Elections. This year the Management Board of Directors (MBoD) has the following openings: *President, 1st Vice President, Treasurer, Secretary and 3 Directors.*

*"With the election of new officers and directors, UOAA experiences a moment of enrichment, a moment of organizational rebirth ... new people, coming forth with new ideas, new enthusiasm, willing to venture along unexplored avenues. Problems cease to be problems and assume the role of opportunities to attain objectives and, in so doing, move on to more expansive goals." ~ Ken Aukett*

The position of **President** is a 2-year term beginning on January 1, 2016 and ending on December 31, 2017.

The position of **1st Vice President** is a 2-year term beginning on January 1, 2016 and ending on December 31, 2017.

The position of **Treasurer** is a 3-year term beginning on January 1, 2016 and ending on December 31, 2018.

The position of **Secretary** is a 3-year term beginning on January 1, 2016 and ending on December 31, 2018.

The 3 directors' positions will begin on January 1, 2016 and end on December 31, 2017.

If you or someone in your group would like to help the UOAA continue with the mission to help ostomates on a national level, please fill out a nomination form. Remember that each form must be signed by the leader of the support group and if that person is the one being nominated it must be signed by another member of your leadership team.

Since the ratification of the new amendments to the Constitution of the UOAA, I am including that for your information. Each candidate for the MBoD should have a copy of this.

Each candidate seeking a position on UOAA's Management Board of Directors is asked to submit a high-quality photo of themselves and to provide a written statement explaining the reason that they want to be a UOAA leader. These statements, photos and a summary of the candidates' experience profile will be sent out with the ballots to ASGs current in their membership dues on April 10th. The candidates' information will also be posted on the UOAA website.

Please note:

Each member of the UOAA Management Board of Directors is obliged to raise or contribute \$200.00 each fiscal year as part of the "Give and Get" fundraising initiative.

If you have any questions, please call the UOAA office at 1-800-826-0826. Remember that these nominations forms need to be returned by **March 13, 2015.**

**Contact Carol Haack at [info@iowaostomy.org](mailto:info@iowaostomy.org) for copies of Job Descriptions, a Nomination form, or the UOAA Constitution.**

The **SHORT CIRCUIT** is the official newsletter of the Cedar Rapids / Iowa City Area Ostomy Support Group #171, and is published 6 times per year.

**MEMBERSHIP** is open to ostomates and their families, friends and caregivers. Dues are \$10 per year and include an **email** subscription to the SHORT CIRCUIT newsletter. Copies are also available free on our website at [www.iowaostomy.org](http://www.iowaostomy.org).

If you wish to subscribe to the **printed edition of the newsletter** there is an *additional* \$10 charge per year to cover the costs of printing and mailing.

Membership dues and print subscription fees are collected on the honor system. If you are reading this newsletter you are a member even if you are not able to attend meetings. Your membership fee is tax deductible and will help support educational activities for ostomates in eastern Iowa. Send membership dues and subscription fees to Vicki Kee, at the address in the column to the right.

Our **WEBSITE** is [www.iowaostomy.org](http://www.iowaostomy.org). It contains helpful information, meeting schedules, archived editions of the SHORT CIRCUIT, ostomy-related books that we recommend, and a link to **Amazon.com**, which pays our group commission each time a purchase is made through our website.

**Officers** of the Cedar Rapids / Iowa City Area Ostomy Support Group  
[info@iowaostomy.org](mailto:info@iowaostomy.org)

**Gina Carlile, Visitor & Membership Coordinator**  
309-292-0150

**Carol Haack, Coordinator & Newsletter Editor**  
319-530-6749

**Vicki Kee, Treasurer**  
P.O. Box 5227  
Coralville, IA 52241  
319-853-8765



# Meeting Schedule 2014 –2015



- Thursday, Feb. 19, 2015 6:30 pm **Support Group meeting** Mercy Medical Center, Cedar Rapids. Park at the east end ramp and enter by the gift shop. Take elevator to lower level. We'll be in Training Room B. ***Join us for a Movie Night!***
- Saturday, April 11, 2015 **Ostomy Education Day** sponsored by WOCN. Mercy Medical Center, Des Moines
- Tuesday, April 21, 2015 **Support Group meeting** St. Luke's Hospital, Cedar Rapids.
- Tuesday, May 19, 2015 **Support Group meeting** UIHC Iowa River Landing clinic, Coralville.
- Thursday, June 18, 2015 6:30 pm **Support Group meeting** Mercy Medical Plaza, Iowa City (across from Mercy Hospital.) Take the elevator to the lower level. We'll meet in the McAuley room.
- Thursday, Aug. 20, 2015 6:30 pm **Support Group meeting** Mercy Medical Center, Cedar Rapids. Training Room B on the lower level
- Tuesday - Sunday Sept 1 - 6, 2015 **5th UOAA National Conference**, St. Louis, MO. Check the UOAA website at [www.ostomy.org](http://www.ostomy.org) for more information during the coming months.
- Tuesday, Sept. 15, 2015 **Support Group meeting** UIHC Iowa River Landing clinic, Coralville.
- Saturday, Oct. 3, 2015 **Ostomy Awareness Day**
- Thursday, Oct. 22, 2015 **Support Group meeting** St. Luke's Hospital, Cedar Rapids.

**Meeting cancellations** — If it becomes necessary to cancel a support group meeting due to weather conditions, the information will be posted on our website: [www.iowaostomy.org](http://www.iowaostomy.org). If you receive the Short Circuit via email, you will also receive an email notice of cancellations. If you suspect a meeting will be cancelled because of inclement weather but don't have access to email, just give Carol or Gina a call to find out the status of the meeting. Phone numbers are at the bottom of page 2.

**Contact information...** looking for information on ostomy products or ostomy –related organizations?

**Manufacturers** - most have an ostomy nurse on staff to answer your questions about products. They'll even send you free samples to try!

Coloplast	888-726-7872	<a href="http://www.us.coloplast.com">www.us.coloplast.com</a>
ConvaTec	800-422-8811	<a href="http://www.convatec.com">www.convatec.com</a>
CyMed	800-582-0707	<a href="http://www.cymed-ostomy.com">www.cymed-ostomy.com</a>
Hollister	800-323-4060	<a href="http://www.hollister.com">www.hollister.com</a>
Marlen	800-321-0591	<a href="http://www.marlenmfg.com">www.marlenmfg.com</a>
Nu Hope	800-899-5017	<a href="http://www.nu-hope.com">www.nu-hope.com</a>

**Suppliers** - will send a free catalog featuring many brands of ostomy supplies. A great way to compare products!

AOS Medical Supply	800-858-5858	<a href="http://www.mmsmedical.com/aos">www.mmsmedical.com/aos</a>
Byram Healthcare	877-902-9726	<a href="http://www.byramhealthcare.com">www.byramhealthcare.com</a>
Duke Medical Supply	888-678-6692	<a href="http://www.dukemedicalsupply.com">www.dukemedicalsupply.com</a>
Edgepark Medical	800-321-0591	<a href="http://www.edgepark.com">www.edgepark.com</a>
Liberty Medical	888-844-2651	<a href="http://www.libertymedical.com">www.libertymedical.com</a>
SGV Medical	800-395-6099	<a href="http://www.sgvmedical.com">www.sgvmedical.com</a>

**United Ostomy Associations of America**  
800-826-0826 [www.ostomy.org](http://www.ostomy.org)

**Wound, Ostomy and Continence Nurses Society** 800-224-9626 [www.wocn.org](http://www.wocn.org)

**Friends of Ostomates Worldwide-USA**  
[www.fowusa.org](http://www.fowusa.org). Donate unused supplies.

**Osto Group** free product for the uninsured  
877-678-6690 [www.ostogroup.org](http://www.ostogroup.org)

**American Cancer Society**  
800-227-2345 [www.cancer.org](http://www.cancer.org)

**Crohn's & Colitis Foundation**  
800-343-3637 [www.ccfa.org](http://www.ccfa.org)

## HELPFUL HINTS

AICM-Montreal Nov-Dec, 2014 Newsletter  
UOAA Update January 2015

**Posture Matters:** When you return from the hospital, you will be feeling sore and uncomfortable. You may be anxious about the front of your body getting bumped, or self-conscious about the stoma which can lead to a habit of hunching over to "guard" that area. Try to focus on keeping your head up and your back straight.

**Walking Works:** Don't lie or sit about all day. Walking helps restore lost muscle tone, gets your circulation going and just generally perks you up. Get up and walk several times a day.

**Stomahesive Paste:** If your stomahesive paste becomes hard and will not push through the end of the tube, heat a glass of water filled half way in the microwave for 45 seconds. Remove and place the tube cap down in the water. Let stand for a few minutes and dry. You should now be able to push the paste out easily.

**Vitamins:** Vitamins should be taken on a full stomach. Otherwise, they irritate the lining of the stomach and produce the sensation of feeling hungry.

**Diuretics:** Try strong-brewed tea before the purchase of a "diuretic". Hot tea twice a day will wake up your sluggish kidneys.

**Juice vs. Gatorade:** Tomato juice provides as much sodium and 5 times more potassium and is a low cost alternative to Gatorade. Orange juice is another alternative providing the same amount of sodium and 15 times the amount of potassium to Gatorade.

**For Colostomies:** If you use just a pad instead of an appliance, use a little K-Y Jelly over the stoma to keep things soft and lubricated. If you irrigate, allowing too much water to enter the stoma too quickly may cause a sudden evacuation of waste, leaving much of the feces still in the colon, along with most of the water. Periodic evacuation may follow. This is not diarrhea, but is simply a delayed emptying of the colon.

**For Ileostomies:** Usually ileostomates experience hunger more often than other people. When this happens, they should drink fruit juice or water, eat soda crackers followed by a meal as soon as

possible. If you do need to eat a snack at bedtime or during the day in order to ward off nausea, try to cut down on calories somewhere else in the daytime or you will gain weight. Never skip meals in order to lose weight. An ileostomy keeps working whether the ostomate has eaten or not.

## SORBITOL: THE HIDDEN LAXATIVE

By Lisa Robinson, Pharm. D., via St. Paul (MN) The Pacesetter  
UOAA Update January 2015

Many factors dictate an ostomate's overall health and wellness. Diet, exercise and adequate vitamin/mineral supplementation are essential for a healthy immune system. Excessive and/or chronic diarrhea increases the speed at which food goes through the digestive tract, which leaves less time and surface area for nutrient absorption. In an ostomate, this may be apparent by the speed at which the ostomy bag fills. Medication therapy in an ostomate is individualized. An oral liquid is generally preferred to tablets or capsules. Many oral solution and suspension formulations contain a sweetening agent called sorbitol.

Sorbitol is a poorly absorbed polyalcohol sugar that is also used therapeutically as a laxative. Therapeutic laxative dosing of sorbitol for an adult is 20-50 grams per day. As little as 10 grams of sorbitol has been shown to cause cramps and diarrhea in patients. Sorbitol is classified as an inert ingredient; therefore, manufacturers do not routinely list the amount of sorbitol. The laxative effects are cumulative based on the total daily dose.

Patients receiving multiple drugs containing sorbitol are more likely to experience adverse reactions. Look at your liquid medication and see if sorbitol is listed under inactive ingredients. If it is a prescription medication, call your pharmacy and ask them who the manufacturer is and if sorbitol is listed as an ingredient. If you are taking several sorbitol-containing medications on a daily basis, you may want to call the manufacturers and inquire as to the sorbitol quantity.

Commonly used liquid medications that may contain large amounts of sorbitol include: acetaminophen, aluminum hydroxide, calcium carbonate, calcium glubionate, cimetidine, dexamethasone, docusate sodium, digoxin, diphenhydramine, ferrous sulfate, furosemide, ibuprofen, lithium, metoclopramide, propranolol and theophylline.

## **WINTER TRAVEL TO FUN AND SUNNY PLACES**

By Patti Burke, RN CWOEN, ET  
UOAA Update January 2015

### *Preparing for Travel*

1. Change your pouch 24 hours before departure to assure complete adherence.
2. Make a list of all supplies you use with their stock numbers. Take photocopies of the catalog that shows the products you use.
3. Call your manufacturer to obtain a list of suppliers in the area where you will be traveling.
4. Obtain a referral list of doctors and medical centers in the area where you will be traveling.
5. Check with your doctor about taking an anti-diarrheal medication to treat any diarrhea that may occur.

### *Packing your Carry-on Bag*

1. Change of clothes.
2. Bring pre-cut wafers/pouches that were prepared at home.
3. Rounded tip scissors can be packed in your carry-on bag. (Check with your airline to be sure.)
4. Pack supplies in carry-on **and** checked luggage.
5. Take twice your normal amount of supplies. (Remember Murphy's Law.)
6. Pack baggies or plastic bags to dispose of used pouches.
7. Obtain a statement from your doctor about your need for ostomy supplies.
8. Urostomates need large plastic bags that zip closed for bedside overnight drainage. Attach the bag with a clothespin to a wastebasket and zip closed close to the drain tube.
9. Colostomates who irrigate should do so only with drinking water.
10. Take an insulated bag to store your supplies in extreme temperatures.

### *Swimming With An Ostomy*

1. Empty your pouch before swimming.
2. Swim when the bowel is less active, usually in the morning. Use pink tape to "frame" your wafer for security.
3. Women should choose a patterned suit with a liner for a smoother profile.
4. Men can wear a tank shirt and trunks if the stoma is above the belt line.

## **STOMA MANAGEMENT**

UOAA Update January 2015

Management of a Flush or Retracted Stoma: The ideal stoma is one that protrudes above the skin, but this is not always possible and a flush (skin level) or retracted (below skin level) stoma may result. The surgeon may be unable to mobilize the bowel and mesentery (membrane that attaches organs to abdominal wall) adequately or to strip the mesentery enough without causing necrosis or death to the stoma.

Some causes of stoma retraction after surgery may be weight gain, infection, malnutrition, steroids or scar tissue formation.

Stomas that are flush or retracted can lead to undermining of the pouch by effluent (drainage). This continued exposure can lead to irritated and denuded skin, as well as frequent pouch changes. These problems can be very stressful and expensive.

The inability to maintain a pouch seal for an acceptable length of time is the most common indication for a product with convexity.

### **Convexity Requirements:**

- Shallow - for minor skin irritations and occasional leakage
- Medium - stoma in deep folds; severe undermining and frequent leakage
- Deep - used when medium convexity is not sufficient, stoma is retracted or in deep folds, or leakage is very frequent and skin denuded.

### **Ways to Achieve Convexity:**

- Convex Inserts: Can be applied to a two-piece system by snapping an insert into the ring of the flange. Outer diameter must match the flange size. This can be cost effective as this insert can be cleaned and reused.
- Pouches Designed with Convexity: These are available in both one and two-piece systems. They can be shallow, medium, or deep. They come as either precut, cut or cut to fit.

- **Addition of Skin Barrier Gaskets:** These are used around the stoma and can be cut or purchased precut. You can use one layer or several layers.
- **Barrier Ring/Strip Paste:** These are products that can be pressed into shape around the stoma to protect the seal.

### **Other Ways to Increase Wear Time and Prevent Leakage:**

- **Ostomy Belt:** Many ostomates find this product to be helpful. The opening should clear your stoma by one-eighth inch only to give the skin maximum protection.
- **Ostomy Paste:** Use this for "caulking" around the stoma. Always read and follow manufacturer's direction for product use.

## **URINE SALT CRYSTAL DEPOSITS**

By Linda Sanders, CWOON  
UOAA Update January 2015

Urine salt crystal buildup around urinary stomas is one of the most difficult skin care problems for people with urostomies. Urine secretes a certain amount of salt, but whether the urine is acid or alkaline determines the amount secreted. An alkaline-based urine secretes more salt than an acid-based urine; thus, more salt-crystal build-up with alkaline urine.

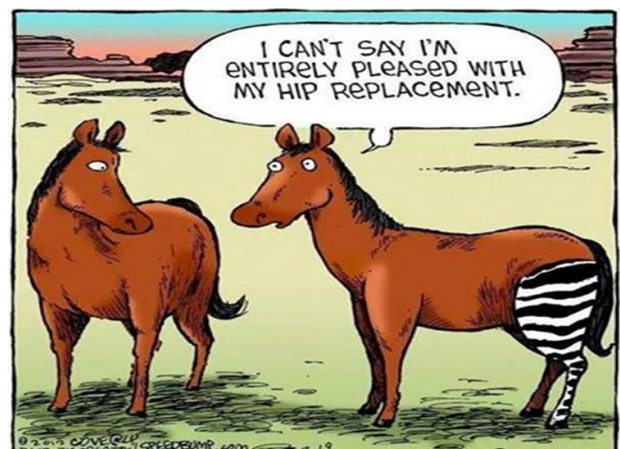
How can you tell if you have urine crystals? First, they can be seen as a growth, white or light brown in color, around the base of the stoma. The stoma and the area, which the growth involves, are very likely to be tender and sore. Sometimes the stoma will be completely covered by the crystals and can no longer be seen.

What are some of the underlying factors which cause urine crystals, other than alkaline urine? In many cases, two factors are usually dominant. The stoma opening in the skin barrier in all cases was too large, and these patients were wearing a pouching system designed primarily for a fecal ostomy. These two aspects may not always stand true, but in those cases I have seen, these two factors were present.

Other aspects include those patients who do not use a night drainage system, thus allowing urine to remain in the pouch while they slept. This practice continually bathes the stoma with urine at night. Moreover, personal hygiene - not only on the skin area around the stoma but the cleaning and proper care of the pouching system - was performed poorly.

What to do in case of a urine-crystal buildup problem:

- Determine the circumference of your stoma and cut your skin barrier to the correct size; i.e., not so big as to allow your Peristomal skin to show, and not so small as to more than just "brush" the stoma.
- Change your pouching system at least twice a week. It is surprising how many people only change their skin barrier when it starts to leak. The goal is to change it before it leaks.
- Every time you change your skin barrier, bathe your stoma with a vinegar and water solution. Use one-part vinegar to three-parts water. Bathe the stoma for several minutes with a cloth. This solution may be used between changes by inserting some of this vinegar solution in the bottom of your pouch - a syringe may be used for this - and let the solution bathe the stoma.
- To keep control of the situation, change the alkaline urine to acid urine. The easiest and most successful way is by taking Vitamin C orally. The dosage will depend on your age, but the normal adult dosage is 250 mg four times a day. Be sure to consult your physician before taking oral medications.





*UOAA UPDATES is how our national organization communicates to all support groups and members about what is happening throughout the organization.*

## PRESIDENT'S MESSAGE



Members and Friends of UOAA,

My hope is that your Holiday Season was a happy and healthy one, and that 2015 will be a wonderful year for you, our Affiliated Supports Groups (ASGs) and partners.

Over the past month we have been reviewing our Strategic Plan from 2014, and how we can implement the awareness programs for your UOAA and our ASGs. The Management Board of Directors (MBoD) is meeting in mid-January to continue to strengthen these programs.

We welcome **Ival Secrest** as the new Chair for the ASG Advisory Board, which works directly with new and existing affiliated support groups and the Management Board of Directors (MBoD). Also, **Al Nua** will be chairing the Ambassador Program, which will identify members who volunteer to help support our ASG's regionally.

We welcome 2 newly elected Directors, **Cheryl Ory** and **Al Nua**, and a new 2nd Vice President, **Joan McGorry**, to the MBoD. They bring leadership and experience to our Board.

Our Social Media team, chaired by **Doug Yakich**, has been working on our "likes" on Facebook, and keeping people informed via all social media. Doug has formed a new team (Alyssa Zeldenrust, Elizabeth Cutler, Keagan Lynggard, and Sierra Cabezas) to assist in ostomy awareness.

The 2nd Annual 5k Ostomy Awareness Run/ Walk will be held again in North Carolina this coming October 3rd, in conjunction with World Ostomy Day. We hope to have additional walks in other regions of the country as well. Please contact the office if this is something your ASG is interested in helping us create.

**Doug Shefsky**, our Advocacy Chair, is also working with a new committee including Past President of WOCN Society, **Margaret Goldberg**, CWOCN, to continue working with ASG members in various states to communicate with their legislators to keep ostomy supplies issues in the forefront. A continuing goal is to pass additional ostomy supply coverage related bills. As always, the committee is looking for anyone interested in leading advocacy efforts within their state.



Our conference committee Chair, **Ken Aukett**, and speaker chair, **Millie Parker**, are working on our 2015 "Gateway to a New Life" conference to be held **September 1-6, 2015**, at the Hyatt Regency at the Arch, in St. Louis, MO. We are holding a full day of ASG leadership sessions on Wednesday, September 2, and you will need to sign up for this on the registration form. Attending a conference can help with strengthening your ASG by offering educational sessions, full exhibit hall, seeing old friends, and meeting new ones. Check our web site [www.ostomy.org](http://www.ostomy.org) for updated information on sessions, speakers and fun activities. Our online registration form is on our web site now! [2015 Conference Registration form](#)

Elections will be held this year for President, 1st Vice President, Treasurer, Secretary, and 3 Directors. We will be sending out election information starting in January 2015. The timeline of the election process is as follows:

### January 5th:

- UOAA office emails election information and blank nomination forms to ASGs

### March 13th:

- Deadline for receipt of submission of nominated candidates

### April 10th:

- Election and candidate information posted on website
- Ballots emailed to ASGs current in their membership dues

### June 30th:

- Deadline for receipt of submission of ballots from ASGs current in their membership dues





**Marty Gelband**, from our Hemet, California, ASG, submitted an idea for your meetings. Have members collect ostomy informational materials, magazines articles, copies of *The Phoenix Magazine*, and newsletters from other ASG's to start an ostomy lending library for new members, Veterans, and WOC nurses. Information and education is always extremely helpful in recovery from all types of ostomy and continent diversion surgery.

The office staff is working to make sure we have the correct contact information for our ASGs. This is critical so that we can communicate with your leadership and members. If there are e-mail address and/or phone number changes for your group, please contact the office at **1-800-826-0826** or email [oa@ostomy.org](mailto:oa@ostomy.org). Although we list only one primary contact per ASG on our website, we will appreciate obtaining a secondary contact person's e-mail address and/or phone number, which will help us get National information to you.

#### **NPS Pharma**

Recently I was contacted by Mary Frances Harmon, Global Head of Patient Advocacy of **NPS Pharma**, who expressed a desire to expand her company's relationship with UOAA by not only providing support at the national level but also through the provision of support at the affiliated support group level. This willingness to provide support to the ASGs would be accomplished through direct contact between the ASG leaders and the **NPS Pharma** representatives.

As background information, **NPS Pharma** is a global biopharmaceutical company pioneering and delivering therapies that transform the lives of patients with rare diseases. They believe that these patients should have access to information, support and treatments designed to improve their health outcomes. One of the company's current therapeutic areas of focus is gastrointestinal disease which includes **Short Bowel Syndrome**, a potentially fatal gastrointestinal disorder in which patients may have to rely on parenteral nutrition for their survival.

In order to best support these patients, **NPS Pharma** has established a team of patient advocates to work directly with patient groups in local communities ... groups like UOAA's ASGs. They can help support meetings, identify topics of interest, secure speakers on various topics, etc.

I concur with Ms. Harmon's assessment that it would be a wonderful opportunity for the ASG leaders and their members if a working relationship could be established with **NPS Pharma**. To accomplish this I would like to introduce these patient advocates to you and provide you with their contact information.

The patient advocate for the **CENTRAL REGION** is **Frank Quintieri 908-672-8513**

[fquintieri@npsp.com](mailto:fquintieri@npsp.com)

Global Head of Patient Advocacy: Mary Frances Harmon 908-450-5625 [mharmon@npsp.com](mailto:mharmon@npsp.com)

Do not hesitate to call upon these representatives; they are looking forward to meeting with you and providing support through you to your ASG and your members.

If you are a Certified Ostomy Nurse from the United States, you are eligible to apply for the **\$400 Galindo Award**, which is sponsored by the Gene Galindo Memorial Fund.

The Gene Galindo Memorial Fund was established in August, 2006 to pay tribute to an individual who was dedicated to improving the life of individuals with ostomies. He gave unselfishly of himself and his talents to clients whenever there was a need. The fund will help to provide financial support to qualified individuals to promote those endeavors that are noted as worthy to continue his dream to educate, assist, support and promote a better quality of life for individuals with ostomies.

Details of the award and application process are available on Pacific Coast Region's website at: [www.pcr.org](http://www.pcr.org). The deadline for applications is midnight, March 31st. Contact person is Candace C. Miller. You may email her with your questions at: [CandaceCMiller@comcast.net](mailto:CandaceCMiller@comcast.net).

Thank you,

Susan Burns  
President, UOAA

**Cedar Rapids / Iowa City  
Area Ostomy Support Group #171, Inc.  
P.O. Box 5227  
Coralville, IA 52241**



***Join us!***

***Next meeting Thursday,  
February 19th, 6:30 pm  
Mercy Medical Center,  
Cedar Rapids***