Our Next Meeting is
Sunday, November 16, 2014
2:00 PM

First PRESBYTERIAN CHURCH
161 N. Mesa Drive
Mesa, AZ. 85201
Meeting in Fellowship Hall

Speaker for November will be Virginia Warren from Arizona Department of Health services. Should be of interest for all available services in AZ.

ET Advisors
We want to thank our WOC nurses for all they have done for us. They come to every meeting and help us with any problems we may have.

Banner Desert Medical Center (Dobson Road)
Contact # 480 412-3449
Janet Schmidbauer, RN, BSN, CWOCN
Elaine Fox, RN, BSN, CWOCN
Angela Hukill, BSN, COCN, CWCN
Jenny Bishman BSN, COCN, CWCN

Banner Baywood Medical Center (Power Road) Contact # 480 321-4642
Karol Friend, BSN, RN, COCN, CWCN

Independent Nurses
Sandy Lane BSN, RN, COCN, CWCN
Miriam Jensen BSN, RN, COCN, CWCN

Support Group Meeting Dates through December 2014. All meetings begin at 2:00 PM at Mesa First Presbyterian Church
November 16, 2014
December 7, 2014

Board Meeting Date:
All meetings begin at 9:30 AM at Mesa First Presbyterian Church
November 01, 2014

UOAA: For information for ostomates and to view upcoming conferences and events, go to www.ostomy.org. You can join the discussion board and read the monthly Update letter. Click the “advocacy” tab to reach your elected officials and send a suggested message

BE SURE TO VISIT OUR WEBSITE:
www.ostomysupportarizona.org
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**Ostomy Supplies:** Kathy Scoles  
480.668.1462  
kathyscoles@cox.net

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**Note from Your President**

My work schedule has changed, so with a "heavy" heart I resigned at our October meeting. I will still be there when I can.

, Darlene

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**Important Contacts for Ostomates**

Coloplast___www.us.coloplast.com___1-877-726-7872

ConvaTec__www.convatec.com______1-800-422-8811

Hollister___www.hollister.com_______1-888-740-8999

UOAA___www.ostomy.org___________1-800-826-0826

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Do not give up, the beginning is always the hardest.
Suggestions box

We would like to start a suggestion box column in our newsletter. Many of you have special little things you do that help you and work for living with an ostomy. It is amazing how little inconsequential ideas can bring great comfort and answers to frustrating happenings. Please share your tidbits. Send your suggestions to Ostomy Support Group EV/AZ, P.O. Box 1681, Mesa, Az., 85211, or email generalkosman@gmail.com, or call 480-812-0324

We look forward to making this column a winner!

50/50 Raffle:

VISITATION Report:
N/A

Sunshine Report:
N/A

New Visitors:

Bob    Breanna
Roxanne    Sharon
Ora    Jack
Lon    Sharon

Refreshments

You have always been very generous bringing refreshments. We have no sign ups, so if you any of you would like to bring something, it would greatly appreciated.

The Nerve(s) of the Stomas!

The question or comment about stomas lacking sensory nerves, or the more broadly stated claim that stomas have no nerves, is a myth that dies very hard. Allow me to borrow from one of my presentations that partly addresses this issue:

“…most of the information carried by gastrointestinal primary afferent neurons is not consciously perceived. This is nicely demonstrated by tests on fistula patients who report no sensation when the healthy stomach is probed or in patients that have had the intestinal lining cut to take a biopsy.” quoted from: Am J Physiol Gastrointest Liver Physiol 277:922-928, 1999. John B. Furness, Wolfgang A. A. Kunze and Nadine Clerc. page G924.

Additionally, we have: “There are more than 100 million nerve cells in the human small intestine, a number roughly equal to the number of nerve cells in the spinal cord. Add in the nerve cells of the esophagus, stomach, and large intestine and you find that we have more nerve cells in our bowel than in our spine. We have more nerve cells in our gut than in the entire remainder of our peripheral nervous system.” quoted from: The Second Brain by Michael Gershon, M.D. page Xiii.

Alas, stomas do have nerves!

So, now let us put to rest the misstatement about the bowel and nerves, and bother to reeducate those who have misspoken early on.

There are nerves; but the sensory nerves of the bowel between the esophagus and the rectum, for certain types of painful stimuli, such as cutting or cautery, are either very low in number and caliber or the brain is not readily able to perceive the pain.

Of course, one can still be a pain in the a**: however, this is a topic for other times and places.
Important News

In our continuing effort to reduce costs and keeping up with “go green”, newsletters to members will discontinue effective November 2014.

Those of you who want a newsletter sent by mail must contact Sandra Clark at: 480-835-1338.

Use our website to attain our news and other valuable articles about our ostomy club at www.ostomysupportarizona.org

WannaWearOne Campaign!

Reprinted from www.ostomy.org

Ostomies are largely misunderstood or not known about in the general medical community. However, in 2010, a WOCN and her boss at the University of North Carolina (UNC) came up with an idea to raise awareness within their medical community. Four years later, it is now the basis for starting a national event, and the program itself is about to go global. The UOAA is proud to announce that the WannaWearOne campaign is officially ready to launch.

The program is very simple:

- Someone takes charge to recruit people to agree to wear an ostomy pouch for three days.
- They pick a date that everyone will start, and each day the participants are given instructions to make it as realistic as possible.
- The leader must contact a local provider of ostomy supplies and ask them to donate the proper amount of pouches to be used.
- The leader uses this opportunity to secure the provider of the ostomy supplies as a sponsor of the party at the end of the campaign.

Day One: Just attach the pouch and go about your day.

Day Two: Participants put water, applesauce or some other substance into their pouch to give them the feeling of how it feels when an ostomate's pouch is filled.

Day Three: Time to remove the pouch and have a party. This is an opportunity to share each other's experiences and also to educate one another about some of the trials and tribulations that were experienced.

During the three days, everyone is encouraged to take pictures of themselves doing activities while wearing an ostomy pouch. They submit these pictures to the leader, and a photo contest can be held to award those most creative!
Then the winners’ photos can be posted on our website for all to see.

I encourage everyone to visit [www.wannawearone.org](http://www.wannawearone.org) to learn more. This program is an excellent tool for our ASGs to reach out to their medical community, share this amazing program, and promote their meetings and resources. I encourage every ASG leader to be a part of this program in each local medical center, as it will build a solid relationship with key people in their medical community. This could help them recruit speakers or learn new topics that they can discuss with their members.

One of our Directors proposed this program to his doctor at UCLA during the week of September 22, 2014. Within 5 minutes he had a co-chair, 10 people signed up, and a goal of getting over 200 people to participate. If reached, the goal of 200 participants would beat UNC, which had 157 last year! UCLA will be participating in this program the last week of October.

I challenge all of you to promote and share this program. The response we have received so far is wonderful. This will be an amazing program for any ASG to partake in

Raising awareness one pouch at a time!

Warmest Regards,

Susan Burns
President, UOAA

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**Worldwide Adventures in Ostomy**
(Can you explain an ileostomy in Turkish?)

By Jack Crosby, 7/8; via Northern Virginia the Pouch

I have just returned from a much needed vacation. After two years of medical misery I was way overdue for some relaxing fun, but I hadn’t factored in how to explain an ileostomy in multiple languages that I don’t speak.

My medical story is pretty familiar to many ostomates – anemia caused by internal bleeding, months of invasive tests in search of the cause, multiple transfusions to keep me going, location of a malignant bleeding tumor, a colon resection, serious ulcerative colitis, a total colectomy and an ileostomy.

Fourteen months after the last surgery I was really ready for what we planned – a trip from Washington DC to Istanbul to be with family for a week, followed by a month in China before returning to Washington for the summer. I downloaded the UOAA Ileostomy Guide and carefully read the section on travel. I followed most of the travel advice in the guide. I bought ample supplies and split them into portions, some for my carry-on and some in each piece of checked baggage. I split supplies so that I could get along for at least two weeks with just the supplies in any individual piece of luggage. I was careful to precut any supplies that would be in my carry-on so that I wouldn’t need anything metal to change pouches. I labeled each set of supplies in English and Chinese. I wrote up a two-paragraph description of an ileostomy in English (and later in Chinese) and kept it with my ticket and passport. I was ready!

The one piece of advice I didn’t follow was to get a letter from my doctor in all of the languages I would encounter. As it turned out, it wasn’t the lack of a letter from a doctor that mattered, it was the lack of any kind of explanation in a language that the security personnel could understand. English was not enough. The first trouble was in an unexpected place, Paris. To get to Istanbul I needed to change planes at Charles de Gaulle airport in Paris.
. At this airport, changing planes means getting into a large bus and being transported to the terminal for the second flight, and upon entering the terminal, going through security. I was still only half awake after the overnight flight and the detection devices were apparently set to a high level of sensitivity. The machines were beeping on almost everyone, and a beep means a frisking.

When I was frisked the security agent felt the ostomy pouch and became somewhat alarmed. Security personnel are trained to be suspicious of anything unusual. He kept asking me what it was in something approaching English but I couldn’t seem to explain it to him and he didn’t want to look at any pieces of paper. He and a colleague kept looking at and touching the pouch and asking me to take off clothing. I refused to take off my shirt and they looked at each other and finally said OK. Of course, by this time about 50 people were staring at me and my pouch.

Attaturk Airport in Istanbul was much worse. I went to the airport to see one of my sons off on his way back to his State Department post in Iraq. As soon as you enter the Attaturk Airport you must go through security and they are very nervous there because of recent terrorist attacks. I had absolutely nothing in any pockets when I went through the detector, but apparently my shoes set off the machine and I was frisked again. The security guard immediately became animated and asked for his colleagues to come over. In less than a minute I was being hustled by two security guards into a private room; they spoke no English and I speak absolutely no Turkish. I kept asking them to call a doctor but it didn’t work. A supervisor soon showed up and he calmed the others down. After looking at the pouch for a while he said I could go. This was not fun!

Knowing I would need to go through security again at Attaturk Airport in a few days, I followed my wife’s advice and went to the medical clinic inside the security perimeter at Attaturk and asked if one of the medical personnel there could write up something that I could use to get past the security staff with no trouble.

The clinic is there to check people who may have some difficulty in flying and for $65 they will check you and, if you are in good health, they will issue a “Safe to Fly” certificate in Turkish and English.

I agreed to the fee and they agreed to do it as soon as the doctor was available. The doctor was sitting just outside the examination room and he was very “busy” watching the Turkish equivalent of CNBC Financial News Network. After about 20 minutes I slowly walked past him and left.

Fortunately on my subsequent trip through security I had figured out how not to set off the alarm at the detector and there was no problem.

During my stay in China I had to go through airport security checks twice. The first time I set off the alarm, but I quickly produced my Chinese explanation of an ileostomy and, using my meager Chinese, implored the female guard to read it. She did, and showed it to a supervisor. This with a few quick words of fluent Mandarin from my son, and we were on our way. On my second trip through Chinese security I was lucky enough to not set off any alarms. I didn’t set off alarms in any US airport. I think this is because they are set to a lower sensitivity.

My advice: Don’t set off the alarms, but be prepared because the detectors are set to very high sensitivity at many international airports. On my next trip I will have a letter from a doctor in multiple languages, and I will have an explanation in multiple languages

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If You Have Internet Access . . .

Our website has been up and running. We have all kinds of information plus links to the national UOAA and Phoenix Magazine. Our current Mail Pouch is on the website in addition to archived ones. Our website address is: www.ostomysupportarizona.org

If you have any questions or suggestions about the website, send an email to: webmaster@ostomysupportarizona.org

Useful websites:

- www.uoaa.org
- www.cancer.org
- www.bcan.org
- www.ccfa.org
- www.nih.gov
- www.ccalliance.org
Get Ostomy Answers!

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Date & Location of initial surgery: ______________________________________________________

Complete this form and bring it to the next meeting or mail it with your check to: Ostomy Support Group EV/AZ, c/o Paula Nelson, 6712 Des Moines St., Mesa, AZ 85205-6827

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