

The Mail Pouch

Ostomy Support Group EV/AZ

May 2012

Our Next Meeting is . . .

Sunday, May 20, 2012

2:00 PM

Centennial Village

130 West Brown Road

Mesa, AZ 85207

Our Program . . .

New officers will be installed followed by a pre-summer Potluck. What to bring? *“Any dish that you are good at preparing or would like to share”.*

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**

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)

Janet Schmidbauer, RN, BSN, CWOCN

Elaine Fox, RN, BSN, CWOCN

Angela Hukill, BSN, COCN, CWCN

Banner Baywood Medical Center (Power Road)

Miriam Jensen, BSN, RN, COCN, CWCN

Sandra Lane, BSN, RN, COCN, CWCN

Karol Friend, BSN, RN, COCN, CWCN

Support Group Meeting Dates through May 2012. (No meetings in June and July).

All meetings begin at 2:00 PM at Centennial Village in Mesa.

Sunday, May 20, 2012

Board Meeting Dates through May 2012. (No meetings in June and July).

All meetings begin at 1:00 PM at Centennial Village in Mesa.

Saturday, May 12, 2012

Officers and Directors

Co-President: Sheila Kollenberg

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Treasurer: Paula Nelson

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Visitation: Bobby King

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Newsletter Circulation: Sandy Clark

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Publicity/Sunshine: Marilyn Justice

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Refreshments: Florence Park

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Advocacy: Sheila Kollenberg

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Installation of 2012 -2013 Officers:

Co-President: Sheila Kollenberg

Co-President: Darlene Kosman

Vice President/Program Director: Vella Owens

Secretary: Maureen Hymel

Treasurer: Paula Nelson

Newsletter Editor: Angelica Otiveros

Visitation: Bobby King

Director/Webmaster/Advertising: Robert Miller

Publicity/Sunshine: Marilyn Justice

Newsletter Circulation: Sandy Clark

Director: Bob Owens

Director: Andrea Pinsker

Director/Membership: Vacant

A WORD OR TWO FROM YOUR PRESIDENT

Dear Friends,

We welcomed seeing our familiar faces at the meeting today; as well as some we had not seen for a while and several new ones. It was good to hear, after all the effort Marilyn Justice has put into advertising, making our meetings known; finally this past week our information was in the **Arizona Republic (Mesa/Scottsdale)** and at least 3 new people were present as a result of reading it. Thanks Marilyn and Thank You Mesa Republic. In giving her Sunshine report, Marilyn then asked "when we know of someone needing a card to bring some Sunshine in their lives, please give her a call: **480 982 4862**".

Kelly Clark did a great job filling in at our **Welcome Table**. Thanks, Kelly.

Bob and Vella, Sue Hill (Retired WOCN) and Ted Cooper (from the Phoenix Chapter) and his little granddaughter Leah manned the Ostomy Table at the **Crohn's and Colitis Walk April 28 in the Phoenix Zoo**. Following the walk, the Walkers ended at the designated site for the event. A HUGE crowd was greeted by Cheerleaders from the Shadow Mountain High School as they crossed the finish line. The support was wonderful from folks of all ages making the Walk. From many **filled** baby strollers to some with white hair and all ages in between. The music was great, pizza delicious, massages 'ooooh'---, and many folks came to the rep tables and found tips and hopefully, resolved some of the problems.

Sheila shared the progress of the **OSPA**, the leadership group representing all satellite support groups around the valley. Due to the Privacy Act in sending a young Ostomate to the **Summer Youth Camp**, we will be sending a check to the Youth Camp for them to select someone. We will specify someone from Arizona be the recipient.

An **A/C storage** unit has been rented nearby for storage of supplies needed for our meetings. Four different families will be sharing in bringing the supplies to the meeting each month and returning them at the meetings end.

The Slate of Officers for 2012/2013 was read. There being no further nominations from the floor, a vote was called for approval. See list. Installation will be at May 20 meeting.

Maureen Hymel read the **Minutes** of the last meeting. Paula Nelson gave the **Treasurer's report**. Bobby King shared there had been no **Visitations** to Ostomates this month. Florence Park thanked those bringing the wide assortment of **refreshments**. We thank Florence and Angelica Ontiveras for always 'serving with a smile'.

We are doing pretty good remembering our **Name Tags**. Be sure and keep them handy in your car.

50/50 Pot for the Youth Camp was won by Vella and donated back to the Youth.

Thanks to Maureen Hymel for producing our Newsletter the past few months. Angelica Ontiveras has graciously volunteered to do the Newsletter after May. Thanks Angelica. Everyone remember to get items to her early.

Darlene Kosman introduced our wonderful **WOCNs**, Janet Schmidbauer, Miriam Jensen, Angela Hukill and Sandra Lane from **Banner Baywood and Banner Desert** as our program. The group was divided into their 'category', **Ileostomy, Colonoscopy, Urostomy** and **Associate** (not having an Ostomy) with questions for each group to discuss pertaining to the needs. Much was shared; much was learned. This is always a 'very welcomed opportunity'. Thanks to each of our **Nurses; we couldn't be the group we are without you!**

Darlene announced the MAY MEETING IS INSTALLATION AND **POT LUCK**. Bring some food to share --- and don't eat before you come -- we want you to be hungry 'cause the food is always good.' Thanks to all helping clean up. We were having such a good time/then someone said it's after 4:00PM, so many pitched in and the room was cleared shortly. We always appreciate **Centennial Villages** allowing us to meet in their facility.

Have a great Spring! Vella & Sheila

Another beautiful sunny Arizona day brought many to our last meeting. Our winter visitors are starting to return to their northern homes and we wish them a safe journey and look forward to their return. If you need to have your newsletter sent to your summer address, please be sure to contact Sandy Clark at (480) 835-1338.

We have been getting a number of referrals for new ostomates and are taking advantage of the skills of our ostomy visitors after their training. We were pleased to see new faces at our meetings.

We are happy to have Angelica Otiveros on board with us doing the newsletter. She will be our new editor, starting in August. Thank you so much Angelica! We would love to have some new participants and new ideas.

From Sue Hill:

Ted Cooper, his lovely granddaughter, Bob and Vella Owens and I (Sue Hill), members of the Phoenix and Mesa Chapters of the United Ostomy Association of America had a great evening on April 28th at the Phoenix Zoo supporting the Crohn's and Colitis Foundation of America Take Steps Walk. Over 1,000 volunteers and walk participants attended the Teams and walkers enjoyed the live music, food, activities and the zoo animals. What an inspiring feeling to see the dedication and commitment from so many around Phoenix who all came together for a great cause. The Arizona CCFA group expects to raise just over **\$100,000** once all monies have been collected and entered.

Nurses

Elaine Fox, RN, BSN, CWOCN
Angela Hukill, BSN, COCN, CWCN
Miriam Jensen, RN, BSN, COCN
Sandra Lane CWCN BSN, RN, COCN, CWCN

Thank you to Elaine Fox, Miriam Jensen, Angela Hukill and Sandra Lane, our wonderful WOCN nurses for facilitating the ostomy specific discussion groups at the April meeting. Special thanks for the attention given to the "ostomy associate" group made up of husbands, wives, significant others, family members and supporters of ostomates. We depend on their love and support and together we depend on your knowledge, guidance, and unyielding care. Many thanks!

Please remember to keep your name tags in your purse, pocket or car and bring them to each meeting. For those of you who do not have a name tag, please check at the check in desk when you arrive. We have several in a basket and one might be yours.

Visitation:

Bobby King reported that 8 referrals and 8 visitations were made.

Sunshine Report:

Marilyn Justice reported that get-well cards were sent to Mary Palmer (Carlton), Sandy Clark, Bob Owens and Juanita Frankinstein.

50/50 Winner:

Vella Owens was the winner of the 50/50 drawing but she generously donated her winnings to the Youth Camp Fund. Thank you Vella!

Refreshments for May:

May 20th meeting is Pot-Luck. Bring a dish and bring your appetite!

East Valley Ostomy Members Travel abroad

WE DID IT!
There was much concern. Should we or shouldn't we, make the 2 week trip to Israel & Jordan. **There is life after an Ostomy!** Bob stood the 16 hour flights each way just fine. Of course he prepared ahead of time. Water was the drink, eating was evaluated and all the other tips that have been shared for flying put into effect. There were 'no surprises' and we were able to take part in the whole trip; sight-seeing, walks, climbs. It was the trip of a lifetime! We will never read the Bible the same again. It makes it come alive in so many ways. Just tell yourself, 'I can do it', and you will.

Bob & Vella Owens

In Remembrance:

Ward Beale, husband of Esther (deceased urostomate) passed away in late April. They were our faithful greeters for so many years—until health no longer allowed it. May they both be at peace.

This summer, make your health maintenance a priority!!! For those with *Inflammatory Bowel Disease*, **General Healthcare Maintenance Fact Sheet** is Reprinted from the Crohn's & Colitis Foundation of America. Check it out:

It is important to continue general health maintenance. While working with your gastroenterologist, also remember to **speak with your primary care health care provider about other important issues including:**

- **Vaccinations:** Adults with IBD should generally follow the same vaccination schedules as the general population. The only exceptions are people on immunomodulators and anti-TNF therapy, who should not receive any live virus vaccines. The best time to vaccinate is when someone is newly diagnosed with IBD, before any immunosuppressive therapy has begun.
- **Oral health:** Among the extraintestinal symptoms of IBD are aphthous ulcers in the mouth, also known as canker sores. These may be caused by the IBD itself, or be secondary to nutritional deficiencies. Although not serious, these ulcers can be quite painful. Mouth rinses and other topical treatments may help relieve the discomfort. Please remember to also see your dentist for routine dental care.
- **Tuberculosis screening:** Screening should be done before immunosuppressive treatment is begun because immunosuppressants can affect the outcome of the test.
- **Periodic blood testing:** The frequency and type of tests depend on IBD medication use and any other medical conditions that exist. A baseline set of tests before starting IBD therapy is helpful to determine medication-associated abnormalities and benefits.
- **Colonoscopies:** These are key in the management of IBD—determining the severity and extent of disease, monitoring the effectiveness of therapy, checking for postoperative recurrence, and screening for colorectal cancer.
- **Tobacco cessation:** In addition to raising cancer risk, cigarette smoking has adverse effects

on lung and heart health. It also has a negative effect on people with Crohn's disease.

- **Osteoporosis monitoring:** Osteoporosis can be a significant medical problem in people with IBD, whose reduced bone mineral densities put them at increased risk for fractures. Bone loss can occur as a result of chronic inflammation and/or with the use of steroids. Most bone loss occurs in the first six months of corticosteroid use. The best course of action in terms of osteoporosis prevention is to minimize steroid use if possible, relying instead on steroid-sparing agents such as azathioprine (an immunomodulator) and anti-TNF medications where appropriate. Supplementation with calcium, vitamin D, and the use of drugs called bisphosphonates while being treated with prednisone and other steroids can also be helpful in protecting your bone health.
- **Blood pressure screening:** Because of some of the medications used in treatment, particularly corticosteroids and cyclosporine, people with IBD who are taking these medications may have an increased risk of secondary hypertension (high blood pressure). In most instances, the hypertension resolves once the medication is discontinued.
- **Depression:** Various factors—including the chronic relapsing nature of the disease and some of the medications used as treatment—make people with IBD particularly prone to depression, affecting between 15 and 35 percent of patients. Screening and appropriate medical treatment are necessary.
- **Ophthalmologic screening:** Corticosteroid use may increase the risk of glaucoma as well as cause some temporary vision changes. In addition, extraintestinal symptoms of IBD may involve the eye.
- **Cancer screening:** Some IBD patients are at increased risk for colon cancer and will need frequent colonoscopies for screening. People with IBD should follow the current recommendations for regular screenings for breast and prostate cancer. Women with IBD on immunomodulator therapy are at increased risk for abnormal pap smears (precancerous findings). Men and women on immunomodulator therapy are at increased risk of certain skin cancers. Careful monitoring and evaluation are recommended.

What's New in Colorectal Cancer Research?

When:
Wednesday, June 20, 2012
8:00 PM - 9:30 PM EDT

Each summer, the American Society for Clinical Oncology holds the world's largest conference for cancer researchers, doctors and other medical professionals. Results from clinical trials and other studies are released, which give scientists a fresh look at treatments that may or may not hold great promise in the march toward a cure for cancer.

Dr. Axel Grothey of the Mayo Clinic will explain what science is now telling us about colorectal cancer and how it may impact your treatment in the near future.

This webinar is brought to you by Fight Colorectal Cancer and the Colon Cancer Alliance.

To register go to the colon cancer alliance website www.ccalliance.org or <https://www1.gotomeeting.com/register/521978665>

Upcoming Events

Events from UOAA website

May 18-19, 2012

UOAA ASG Leadership Seminar, Waterbury CT

June 8-10, 2012

Get Your Guts in Gear – New York Ride

July 9-14, 2012

Youth Rally, Boulder CO

August 15-18, 2012

UOA Canada Conference, Toronto, Ontario

August 25, 2012

UOAA ASG Leadership Seminar, Jacksonville FL

September 7-9, 2012

Get Your Guts in Gear – Midwest Ride

October 6, 2012

World Ostomy Day / Ostomy Awareness Day

August 7-10, 2013

4th UOAA National Conference, Jacksonville FL

Colon Cancer Alliance online Calendar

http://www.ccalliance.org/bluestar_calendar/index.html

Reprinted from UOAA website

Ostomy Travel Tips

New: Download UOAA's [Travel Communication Card](#) as an aid in dealing with airline security.

In these days where extra precautions for security are being taken worldwide, it would be wise for traveling ostomates to do advance planning in order to avoid possible problems. Some suggestions are:

1. Pre-cut all pouches at home, as you may wish to avoid having scissors in your carry-on luggage (see [additional comments below](#)).
2. Pack ostomy supplies in at least 2 places – carry-on and checked luggage.
3. Take extra supplies in case you are stranded where supplies may not be available.
4. A statement from your physician stating your need for ostomy supplies might be helpful. Also a statement advocating a private area be used in case of an extended search.
5. If traveling to a foreign country it is a good idea to have critical ostomy information written in their language. One of the 70 member associations of the [International Ostomy Association](#) (IOA) may be of help with this translation as well as with locating supplies while visiting their country.
6. A copy of the book "[Yes We Can](#)" has many helpful hints and advice for traveling and also has a dictionary of ostomy terms translated to several different languages. There is important contact information for resources worldwide as well as a wallet-sized statement written in 11 languages that asks for privacy if a search is to be conducted.
7. One ostomate reported a very positive result from carrying photocopies of the catalog pages displaying and explaining his equipment. When a searcher asked about the items found on a hand search, he was able to explain their function without a long conversation that would hold up others in line. Our experience has been that over time the TSA agents are much more

knowledgeable and sensitive to these personal care products.

About carrying scissors on board aircraft: In the aftermath of Sept 11, 2001, pointed metal scissors were banned from carry-on baggage (they are still always allowed in *checked* luggage). Since then, the U.S. [Transportation Security Administration](#) (TSA) has relaxed the prohibition of scissors in carry-on luggage. In August 2005, TSA allowed a [special exception for "ostomy scissors."](#) In December 2005, they [relaxed the rule further](#) to allow any metal scissors with a cutting edge no greater than four inches. It must be understood, however, that this applies only to flights departing U.S. airports, as the rules vary greatly in different countries. For [flights departing Canadian airports](#), scissors were banned from carry-on baggage until recently (as of early 2011), but they do allow small scissors with blades no longer than 6 cm (2.4 inches) now.

All screening at airports must be conducted in a way that [treats passengers with courtesy, dignity, and respect](#). You may request that any personal screening be conducted in a private area. See TSA's info on [Travelers with Disabilities and Medical Conditions](#).

Restrictions on liquids, gels, aerosols: On Aug 10, 2006, TSA banned all liquids, gels and aerosols from carry-on baggage, with only a few exceptions for required medications, baby formula, diabetic glucose treatments, etc. On Sept 25, 2006, they [modified the rules](#) so each passenger may carry travel-size toiletries (3 ounces or less) that fit comfortably in a single, one-quart-size, zip-top, clear plastic bag—which you must remove from your carry-on bag and place in a bin or on the conveyor belt to be X-rayed separately (see [TSA's explanation of these procedures](#)). Also, beverages and other liquids purchased in the secure area beyond the passenger screening checkpoint can be carried onto the plane. Based on these rules, you should have no difficulty carrying a 2-ounce tube of stoma paste or a few remover wipes, barrier wipes, etc. Remember that the restrictions apply only to carry-on luggage; you can pack as much as you want in your checked luggage. If you need to carry larger quantities of liquid medications, baby formula, etc. on-board the plane, they must be declared separately at the security checkpoint; TSA provides a [form you can use for declaring them](#).

Ostomy Awareness Day "Let's Be Heard"

Saturday, October 6, 2012

"Let's Be Heard" is the theme of World Ostomy Day 2012. The UOAA will be celebrating Ostomy Awareness Day in conjunction with World Ostomy Day on Saturday, October 6, 2012. Let's make this a World Ostomy Day and Ostomy Awareness Day a day that will impact the lives of ostomates, future ostomates and their families!

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.bcan.org

www.nih.gov

www.cancer.org

www.ccfa.org

www.ccalliance.org

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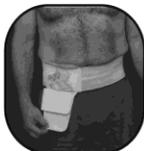
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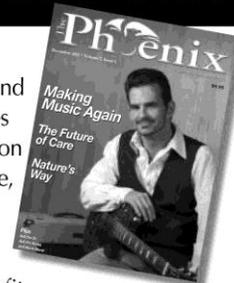
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