

Volume XLI Issue No. 2

February 2011



Broward Beacon



Next Meeting:

Sunday, March 6th, 2011: 1 p.m.

**The Lueders
2100 South Ocean Drive #16M
Fort Lauderdale, FL 33316**

Broward Ostomy Association



An affiliated chapter of the United Ostomy Associations of America.
Our Vision ~ a society where people with ostomies are universally accepted and supported socially, economically, medically and psychologically.

www.browardostomy.org
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Shedding The Light Of Hope, Help, And Education For Ostomates Through Visitation & Rehabilitation.
Published by the *Broward Ostomy Association*, a non-profit affiliated chapter of the *United Ostomy Associations of America* to aid Colostomates, Ileostomates and Urostomates.

MEETINGS: Held on the 1st Sunday of each month September through May and the second Sunday of June at 1:00 P.M. at the Memorial Regional Hospital, Main Auditorium, 3501 Johnson St., Hollywood. Directions: Exit I-95 at Hollywood Blvd. westbound. At 4th traffic light turn RIGHT (north) onto N 35th Avenue. Continue to second traffic light. Turn left following posted signs to Main Entrance. Free covered parking will be on your right and the Main Entrance will be on your left. The Main Auditorium is just off the main entrance lobby. A receptionist as well as security personnel are on duty to assist you.

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Broward Beacon

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President's Page

I was very surprised to find myself being able to attend our February 6th meeting as I thought I would still be in hospital recovering from having a new stoma created on my tummy. After being re-evaluated ten days before the scheduled surgery by Mary Lou, the wonderful CWOC Nurse at Cleveland Clinic Weston, the surgery was indefinite postponed, for which I am totally grateful to the Lord. Truly an answer to prayer.

And, as promised in the previous issue of this newsletter, if I learned anything else that surprises me after being an ostomate since 1972, I'll be sure to let you know. Well I have.

My recent physical difficulties, beside reinforcing the concept that each ostomate is unique and what works for one of us does not necessarily work for another, I recently learned that I have been giving incorrect advice about the use of adhesive removers.

Many years ago a biochemist whose wife was an ostomate told me that adhesive removers, even after being washed off, leave a residue deep in the skin which can cause poor adhesion. Thus he cautioned me on their use.

As I usually went about a week between changing my adhesive skin barrier wafers, and as their removal was relatively easy for me after that long of a wear time, I incorrectly concluded that the use of adhesive removers was not necessary. Wrong!

Lately, when I was having such difficulty keeping my pouch on due to a stoma that was simply disappearing into my body, I needed to change skin barrier wafers quite frequently. The adhesive attachment was thus much stronger due to the shorter wear time and using adhesive remover was a must in order not to injure my skin.

I have correctly advised to always push your skin in toward your body releasing your skin from the wafer and NOT pulling the adhesive skin barrier wafer away from you which can damage your skin.

So bottom line: If your wafer can be removed easily by pushing your skin toward your body, don't use adhesive remover as it can leave a residue which makes future adhesiveness more difficult. However, if you have to change wafers frequently, and removal is difficult, by all means use adhesive remover. Be sure to use one that doesn't burn or sting. A personal recommendation would be Uni-Solve by Hollister. Though I must say I haven't tried other brands for many years, brands that may work just as well.

I urge our members to share any of their learning experiences. It's so easy to become dogmatic when what we really need is open minds and open hearts.

On that note, I hope you all had a wonderful Valentine's day and I truly look forward to being with you all again in the very near future.

Fondly,

Wendy

UOAA's Cares Program

UOAA is once again sponsoring the CARES program to provide financial assistance up to \$650 to new ostomates to attend the National Conference in Reno NV August 7-11, 2011. Going to a UOAA National Conference can be a life-changing event for a person with a new ostomy.

A CARES selection committee, overseen by the UOAA Management Board of Directors, will review all applications. Sponsorships are given in order of preference to people who:

- Have had surgery within the last year

- Are attending a Conference for the first time
- Would be unable to attend without support

Applications are to be filled out and returned to Wendy, your Associated Support Group President. The ASG President must sign, and submit your applications to the UOAA CARES Program selections committee no later than March 15, 2011. Applicants who are selected as finalists may be required to provide further information documenting financial need. All applicants will be notified of the selection committee's determinations no later than May 1, 2011. This is a wonderful program I hope one of us can use.

Next Meeting:

Sunday, March 6th, 2011

Refreshments, 1:00 p.m.

Chat 'n' Chew till 1:30 p.m.

Meeting: 1:30 p.m.



The Broward Ostomy Association is deeply honored to welcome Alok Shrivastava, M.D. of Cleveland Clinic Weston as our March guest speaker.

Dr. Shrivastava is a leading expert in the latest development of robotic ostomy surgery.

This type of surgery greatly reduces the amount of trauma to the ostomate thus allowing greatly moderated recovery time and discomfort.

Yesterday I received a phone call from one of BOA's new members who will be having this surgery with the doctor early in March. Our member shared how caring, knowledgeable and kind the doctor was, putting his mind at much greater ease. Don't miss this exceptional opportunity to learn from a surgeon who is not only highly skilled but compassionate and concerned. Looking forward to seeing you there.

Minutes February 2011

President Wendy opened the February 6th, 2011 meeting at 1:30 p.m. on Super Bowl Sunday with Memorial Hospital's CWOC Nurse Lea reading the Ostomate's Prayer. About 50 people were in attendance including first time guests Lisa, Ed, Jerry and Lillian. Telephone Committee Chairwoman Helen brought three generations of her family: herself, her daughter Susan and her granddaughter Elizabeth. Cy and Addie were welcomed back down from up north in New York and Wendy reminded everyone that our *Broward Beacon* newsletter is sent to all members who visit seasonally and may live away from us for part of the year.


Patricia Paxton-Alan, who leads the Coral Springs Ostomy Support Group, was in attendance along with Steve and Marsha, guests from the Coral Springs Group. Wendy recently was a guest speaker there.

Paula continued gathering support for the 2011 *Take Steps for Crohn's and Colitis* in which she will participate on April 16th starting at the Huizenga Plaza on the Las Olas Riverfront in Fort Lauderdale. Her goal is to raise \$150 and donations are tax deductible.

Wendy introduced today's speaker: Certified Wound Ostomy Continence Nurse and National Researcher Jane Fellows from Duke University. Jane reported results from a *Quality of Life Following Ostomy Surgery* study in which 335 ostomates participated. Each filled out a questionnaire called the Ostomy Adjustment Inventory (OAI-23) where 23 items with positive and negative aspects were rated by participants. Those who participated in the study were required to have had a permanent stoma for a minimum of six months and be over 18 years of age.

An overview of the study showed that the longer a person has lived with a stoma, the better their outlook on their life. The most common complication is peristomal skin problems. Of the survey participants 72% accepted their stoma, 68% disagreed that they had a psychosocial preoccupation about having an ostomy, 58% do not have problems with leakage and 51% say their ostomy has no effect on their diet. The average wear time of appliances is 4.2 days when all types are included.

After her initial presentation, Jane fielded a wide variety of questions from the audience. There was no dramatic difference between manufacturers. Nu-Hope support belts were discussed along with a personalized Nu-Hope ostomy pouching system. Hernias are a frequent concern of people with ostomies, including deciding between surgical and non-surgical treatment. A physical therapist can help determine which exercises are good for you. A resource in finding an ostomy nurse when moving to a new city is the website www.wocn.org. There you can search for a WOC Nurse in the patient care section. Ostomy support groups can be found for your area on the UOAA page at www.ostomy.org.



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SEE YOU IN RENO NEXT AUGUST

JOIN US in RENO August 7—11, 2011 at John Ascuaga's NUGGET (see www.janugget.com). Rooms start at \$79 for a Single or double + tax. Free shuttle from Reno airport (RNO). (Hint: The City of Reno is featuring "Hot August Nights" so get your airline reservations early)

For Hotel Reservations: Phone 800-648-1177 and mention "GOSTOMY". On-line at www.januggetsecure.com/jump/1052/. For Conference Registration: Fee before June 15, \$90 single, \$50 spouse; after June 15, \$110 single and \$70 spouse. Use the form in the Spring Issue of The Phoenix magazine, or On-line at www.UOAA.org.

Featured Events Include:

August 8th: First Timers Orientation and Coloplast sponsored Reception; First Night Ceremonies and Hollister sponsored Fashion Show and Welcoming Social.

August 9th through the 11th: FREE Stoma Clinic consultations with WOCNurse (by appointment) and Hospitality Room.

August 9th - Awards and Keynote speaker; Edgepark Sponsored "Ostomy Basics" workshops; Exhibition Hall; Spouses Chat; ConvaTec sponsored GALA Evening.

August 10th: Traditional Nu-Hope sponsored "Fun Run"; Hollister sponsored medical presentation; Free Box Lunch in the Exhibition Hall; Visitor Training Program

August 10th through 11th: Educational Workshops of special interest to: All attendees; 30+; Young Adults; those with Continent Diversions; gay and

lesbian ostomates; and ostomy support group leaders.

August 11th: Closing Ceremony with motivational send-off and Conference photographic wrap-up; Reception followed by Dining and Dancing with live music at the closing Banquet.

Conferences are only held every two years and they provide a wonderful opportunity to network with others facing the same challenges. Ren and I hope to attend and we'd sincerely love for you to join us.

TSA ADVOCACY NEWS

by Linda Aukett, UOAA's Advocacy Chair

Planning a flight? We have some news and a new blue travel card. If the airport has an Advanced Imaging or AIT machine, you can choose to go through it -- OR you can have a pat-down. At a recent meeting I learned some other things that went into effect in January 2011:

- If the airport has AIT and you choose to go through that, have your blue card ready in your hand (see below). So if the person reviewing the scan (in a remote location) notices something in the area of the pouch, the reviewer will communicate it to the TSA Officer (TSO) through an earphone, and a TSO in the screening area will need to check out the area. But they are not to do a full-body pat-down then, only the questionable area mentioned to the TSO by the scan reviewer.

- If they become aware of your pouch, they are not to ask you to show the pouch - but they will ask you to run your hand over it (outside your clothing) and they will test your hand to rule out explosives residue.

- For any of the above, you can ask for a private screening and you can take a travel companion with you if you wish. There will be 2 TSOs and obviously they should be of the same gender as you.

Our airport (Philadelphia) has only one of the current-500 AITs, in a remote terminal. My husband has knee implants so he sets off the older metal detector and then they pat him down. I go right



through. If we did have to go through an AIT, it would not show his implants, but it would likely notice his pouch – and mine too. So, we carry the special blue card developed by the TSA. You can get to it right from the first page of the UOAA website. Here's the direct link where you can print it out on a standard sheet of paper (in colored ink), trim and fold for carrying: http://www.ostomy.org/ostomy_info/pubs/Travel_Card_2010.pdf.

It is not a pass, but is intended to be a way you can communicate to the TSO in a more discrete manner. The distinctive blue color is something they have been trained to recognize. They may not really read it - we find that they are not taking the time to read doctor's note (too easy to forge). Their goal is to get people moving on their way as fast as possible, but safely.

If you feel you have been treated poorly, ask for a supervisor, and later please file a complaint with the TSA at <https://contact.tsa.dhs.gov/DynaForm.aspx?FormID=10>, or contact me to be referred to the TSA's Office of Disability Policy and Outreach.

Editor's Note: BOA will have full color printed copies of this new blue card available at our meetings. A very small donation to cover our printing costs would be appreciated but not necessary. Our cost 50¢/card. Thank you!

WHERE DO YOUR UOAA AFFILIATION FEES GO?

Every December BOA and every other UOAA Affiliated Support Group receives an invoice for affiliation fees and many of you don't know what we do with the \$2.00 per member. In the next few months we'd like to let you know how important that fee is to the mission of the UOAA.

The first line of contact for some new ostomates is the mention of the 800 number. It is usually located in some publication that has been passed on to them by their doctor, nurse, supplier or manufacturer. Until they make that first phone call to this office the new ostomate believes that he is the only person

in the world that has an ostomy. The feeling of isolation may be profound. The office takes about 20 - 30 calls a day. At least 10 times a day the calls are from new ostomates looking for some comfort and guidance. I know the sound of the caller's voice: timid and afraid to say the word "ostomy". As soon as I tell them that I, too, have an ostomy there is an audible change in their voices. They have found someone like them that has been down the road they are on today.

Your \$2 per member affiliation fee helps to keep this 800 number operating. Phone service, internet service, utilities, etc. are all necessary to keep this service available to those that need a friendly, caring person ready and able to help them.

Joan McGorry

UOAA Director of Administrative Services



Special Offer from the Phoenix Magazine

The Phoenix is America's leading ostomy magazine providing information, management techniques, new products and much more. Each 72-page issue features professionally written, in-depth articles on topics new and experienced ostomates care about; life stories of recovery after surgery; ostomy care advice in *Ask the Ostomy Nurse* and *Ask the Doctor*; and living a full life with an ostomy pouch.

As one reader commented, "I love the magazine and recommend it to everyone that has or will be getting an ostomy. It is always so informative and packed with wonderful tips, suggestions, etc." For a limited time, NEW subscribers to *The Phoenix Magazine* can receive five issues for the price of 4! This special offer is ONLY available to new subscribers through their affiliated support group. Submit the original ad on page 12, along with payment to the address listed on the form.

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Memorial Hospital West is dedicated to addressing the unexpected and changing needs of people who are preparing for or living with an ostomy. We can help with ostomy care, including:

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BOA Minutes *continued from page 4*

Wendy presented speaker's brownies to Jane along with a Plaque of Appreciation for her wonderful presentation. A final note was made of an important Board of Directors meeting that will be held in March in the auditorium after regular meeting. Members are encouraged to attend. The general meeting was adjourned at 2:30 p.m.

Respectfully submitted,



Bill Wilson

Recording Secretary

The Empowered Patient by Elizabeth Cohen

*Book Review by Barbara Hawes, Newsletter Editor
Ostomy Support Group of N Virginia*

The facts are alarming: Medical errors kill more people each year than AIDS, breast cancer, or car accidents. A doctor's relationship with pharmaceutical companies may influence their choice of drugs for you. The wrong key word on an insurance claim can deny you coverage. But there's good advice. CNN's Elizabeth Cohen (Senior Medical Correspondent) shows you how to become your own advocate and navigate the minefield of today's health-care system. Discover how to:

- Find a doctor who "gets" you and listens to you
- Ask the right questions for the best treatment
- Make the most out of a short office visit
- Cut out-of-pocket costs for prescription drugs
- Harness the power of the internet for medical issues
- Fight back when claims are denied.

Combining the personal stories of patients across America with crucial advice on receiving the best possible health care, this guide will enable you to confront an often confusing and perilous system and come out ahead.

Cost is \$15 through major book outlets; \$8.46 amazon.com. I found this book fascinating and I think every member should have a copy.

Frequently Asked Questions

from Metro Maryland Ostomy Association

How do I know if my stoma is healthy? Each person's stoma is unique. The stoma is always red and moist, much like the mucus membrane in your mouth. A stoma is not painful, as there are no nerve endings in it, but many blood vessels near the surface. Minor, temporary bleeding of the stoma is normal if it is rubbed or hit.

What is the skin barrier? The skin barrier is the "waxy" part of your pouching systems that sticks to your skin, primarily responsible for holding your pouch to your body. Manufacturers have developed many kinds of skin barriers, including thin pectin-based wafers, transparent sheets of "breathable" plastic film, pastes and powders. There are wipes and sprays called skin sealants or protectants.

Sometimes these are used under the skin barriers, helping to protect the surface layer of skin from frequent pouch changes. When sealants are used, they need to dry thoroughly before anything is put over them.

Will you make noises? Everyone produces gas. Normally people release gas about 15-20 times a day. Air-swallowers produce even more. You do not make noises so often that you cannot pretend that your stomach is growling. Be the fastest elbow in the west: place your forearm firmly against the stoma. Sometimes wearing a two-way stretch binder, girdle or panty-hose to muffle the sound when it is audible.

Avoid skipping meals, gassy foods, carbonated drinks, drinking through a straw and chewing gum. Eating slowly, sipping rather than gulping and not talking while eating can reduce air swallowing for those with a fecal ostomy to lessen gas passed through the ostomy.

Will you smell?: No! Those with any type of ostomy

Continued on page 10

Frequently Asked Questions *cont. from page 9*

will be fitted for pouching systems, which are completely odor-proof, virtually all that are sold now are. Moreover, one can achieve odor control through diet. In addition, for all people with ostomies there are deodorants for external use and odor-reducing compounds to be taken by mouth, should they be needed.

Editor's Note: I use a wonderful product, NeutralEz™ Tabs created and manufactured by an ostomate. It's a small blue tablet that adheres to the inside bottom of your pouch. Any contents of the pouch that come into contact with the tablet are deodorized. I love it. Takes the worry out of using public bathrooms. You just set it and forget it.

See: <http://www.neutralez.com/> or call 877-396-3887 to request a sample.

Types of Pouching Systems

via Hot Springs Ostomy Support Group

Pouching systems may include a one-piece or two-piece system. Both kinds include a skin Barrier-wafer (faceplate in older terminology) and a collection pouch. The pouch (one-piece or two-piece) attaches to the abdomen by the skin barrier and is fitted over and around the stoma to collect the diverted output, either stool or urine. The barrier-wafer is designed to protect the skin from the stoma output and to be as neutral to the skin as possible.

Colostomy and Ileostomy Pouches: These can be either open-ended, requiring a closing device (a clamp or tail clip); or closed and sealed at the bottom. Open-ended pouches are called drainable and are left attached to the body while emptying. Closed end pouches are most commonly used by colostomates who can irrigate (see below) or by patients who have regular elimination patterns. Closed end pouches are usually discarded after one use.

Two-Piece Systems: These allow changing pouches while leaving the barrier-wafer attached to the skin. The wafer-barrier is part of a flange unit. The pouches include a closing ring that attaches mechanically to a mating piece on the flange. A

common connection mechanism similar to that used in Tupperware.

One-Piece Systems consist of a skin barrier-wafer and pouch joined together as a single unit. Provide greater simplicity than two-piece systems but require changing the entire unit, including skin barrier, when the pouch is changed. Both two-piece and one-piece pouches can be either drainable or closed.

Irrigation Systems: Some colostomates can irrigate, using a procedure analogous to an enema. This cleans stool directly out of the colon through the stoma. This requires an irrigation bag with a connecting tube (or catheter), a stoma cone and an irrigation sleeve. A special lubricant is sometimes used on the stoma in preparation for irrigation. Following irrigation, some colostomates can use a stoma cap, a one- or two-piece system which simply covers and protects the stoma. This procedure is usually done to avoid the need to wear a pouch.

Urinary Pouching Systems: Urostomates can use either one or two piece systems. However, these systems also contain a special valve or spout which adapts to either a leg bag or to a night drain tube connecting to a special drainable bag or bottle.

There are also a number of styles. For instance there are flat wafers and convex shaped ones. There are fairly rigid and very flexible ones. There are barriers with and without adhesive backing and with and without a perimeter of tape. Some manufacturers have drainable pouches with a built-in tail closure that doesn't require a separate clip. The decision as to what particular type of system to choose is a personal one geared to each individual's needs. There is no right or wrong choice, but each person must find the system that performs best for him or her.

The larger mail-order catalogues will illustrate the types and styles from all or most of the suppliers. If you have any trouble with your current pouching system, discuss the problem with an ostomy nurse or other caregiver and find a system that works better for you. It is not uncommon to try several types until the best solution is found. Free samples are readily available for you to try. There is no reason to stay with a poorly performing or uncomfortable pouching system.

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If you wish to be a member of BOA dues are \$10.00 per year from January 1st to December 31st and includes receiving our monthly newsletter, the ***Broward Beacon***. Please make checks payable to BOA and mail to Treasurer Mr. H. Lynn Ward, 1704 N 32nd Ct, Hollywood, FL 33021-4427. BOA never shares membership information. We value your privacy.

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☐ I am an ostomate. I want to be a dues paying member.

☐ I am also enclosing a contribution to BOA

☐ I am an ostomate and want to be a member but cannot afford dues at this time.
(This information is kept in the strictest confidence.)

☐ I would like to become an Associate Member (non-ostomate).



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