

Volume XLII Issue No. 6

August 2012



Broward Beacon



Next Meeting: Sunday Sept. 2nd 1:00 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 and Vice President's Page September's catered luncheon

I asked our wonderful Vice President and Program Chairwoman Amy to write to you about some wonderful news. The following is from beautiful Amy:

"Life is so special when kind people pay it forward! A movie by that name with Kevin Spacey and Helen Hunt focuses on doing good deeds and keeping the chain of goodness flowing. A young boy's social studies project asks the recipient of a favor not to pay it back but instead to pay it forward to three other people, creating a wave of decency and kindness.

Joyce Hoffman is doing just that for our September BOA meeting. Joyce, my friend whose daughter had an ileostomy many years ago, recently attended the Book of Hope Luncheon in Boca Raton to raise funds for the Crohn's Colitis Foundation of America. In the raffle drawing she won a \$ 250 gift certificate to *Subway Restaurant* which must be used all at one time before October 1, 2012.

Joyce called me to donate it to one of my support groups, and BOA was the obvious choice !

So, thanks to Joyce for her generosity and to *Subway* for providing our September luncheon. We hope everyone will enjoy the delicious spread and commit to paying forward three acts of kindness that will make a world of difference. In our circle, we can do so simply with a phone call, a word of encouragement, a hug, a small donation, or a knowing smile."

Thank you Amy for making us your "obvious choice". You continue to love and serve BOA in the most gracious manner. We all adore you.

BOA could simply not exist in its present form without the selfless and gracious assistance of our sponsors who have chosen to place helpful information as boosters in all the issues of our *Broward Beacon*.

As the content of our boosters always change over the summer months please take extra time and effort to look carefully at each page.

Ostomy Inc. is now supporting us with a full page and also has removed the expensive burden of mailing our donated supplies to a wonderful charity, *Ostogroup*, who in turn donates the supplies to those without insurance, being reimbursed for only the cost of postage. Julie and her company also filled in the monetary shortage needed to send LT to Youth Rally this summer. Thank you Julie!

We also have a new booster you will want to view, *HomeCare America* on page 11 and there are major important changes you'll want to note on page 8 in regard to *Memorial Healthcare System's* expanded ostomy services. Eula and Lea we love you! Our wonderful Rob Seaman updated ConvaTec's booster on page 12. We simply cannot thank you enough. When you purchase any of our booster's products or use their services please let them know how much you appreciate their BOA support.

This summer has been a real challenge, one of which I know many of you are intimately acquainted; radiation and chemotherapy for my dear niece. We're still in the deep valley now but are looking forward hoping for brighter days.

Fondly,



How to Change Your Appliance

by Wendy Lueder

Editor's Note: In our last issue we ran out of space to include additional tips about changing your appliance that apply only to ileostomates and colostomates whose colostomies function in the same manner as ileostomates with a constant flow or output. These tips are too important to not share so we will pick up here in this issue of the *Broward Beacon* where we left off

this past June. Also BOA's thoughtful member Gerry Herbert, after reading the article rightly noted that we needed additional tips for urostomates. Please see his wonderful advice below. Thank you Gerry!

Hints for ileostomates and constant output colostomates: Try changing first thing in the morning when output is at its slowest. Many ileostomates report that eating four to five marshmallows right before
continued on page 4

Next Meetings:

Sunday, Sept. 2nd, 2012

Refreshments, 1:00 p.m.

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

Meeting: 1:30 p.m.

When I attend national and regional UOAA meetings I have become aware that we here in Broward County are exceptionally blessed to have a host of loving and knowledgeable certified ostomy nurses. We are so fortunate to have one of them join us in September speaking on "What Not To Put Up With". It is so important to understand which boundaries we as ostomates should enforce. Should I put up with leakage, and if so how often is too often? Should I put up with odor, itching skin, not swimming, limited intimate relations? Find out the important answers to these and many more questions.

Debbie Walde CWOCN graduated from nursing school in Ohio May 1979. That was during the time that enterostomal therapists were a new idea. She started her nursing career working on a med/surg floor that specialized in urology. They had quite a few ileal conduits in those days (no continent ones) and the staff did their own problem solving with getting appliances to stay on.

From there, Debbie went on to working in renal failure including all forms of dialysis as well as transplant workups and follow throughs. She also worked on a locked psych unit for 10 years but moved to Florida the month before 9/11. Most of her time here has been at Broward Health Medical Center (formerly Broward General) where she has been employed in the Atrium ICU which is the trauma, stroke, and liver transplant intensive care in that facility. During this time, Debbie became an active member of SWAT (skin, wound assessment team) where she met her favorite, the great Amparo Cano whom she considers her mentor. Amparo encouraged Debbie to attend Emory University for WOCN. We congratulate her on becoming a Certified

Wound Ostomy Continence Nurse this year. Yeah Debbie!

We are thrilled to learn that our youth rally camper LT has been adopted and will be moving to PA August 17th. The only sad news is that he won't be available to give us a report in person on how much he enjoyed the camp you enabled him to attend. However, LT being the resourceful 14 year old young man that he is has provided us with photos and a short movie to send his farewells.

Coral Springs Ostomy Support Group

Coral Springs Medical Center's "Caring & Sharing Ostomy Support Group" meets on the 4th Wednesday of the month at 5:30 p.m. to 7:00 p.m. For more information call Patricia Paxton-Alan MSN, ARNP-BC, CWOCN at 954-344-3094.

2012 Meetings Schedule

If you are as forgetful as I am here are the dates of our upcoming meetings so you can put them in your date book now. September 2nd, October 7th, November 4th and December. 2nd. Our December meeting is our Holiday Banquet and this meeting only starts at 4:30 p.m. for a wonderful catered dinner. Detailed meeting information including a useful map can always be viewed on our website www.browardostomy.org.

How to Change your appliance

continued from page 3

changing stops all output from the stoma for several minutes. I personally have found this to be true. As marshmallows are pure sugar, please don't try this if you're a diabetic.

As the output for ileostomies is far more caustic containing bile salts and active digestive enzymes than for colostomates with firmer output and all urostomates, don't put off changing your appliance when needed. There are two indications you need to change, one is "itching" and the other is a "burning" sensation. If you itch, it may be merely dehydration. Drink a class of water. If the itching continues, you

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How to Change *continued from page 4*

need to change. If you feel a burning sensation on the skin around the stoma, change as soon as possible. The output from your ileostomy is caustic and will damage your skin. Avoid the vicious cycle of damaged skin -> poor adhesion due to damaged skin -> leakage -> damaged skin.

Urostomy Hints and Tips

Additional Hints to Wendy's Ostomy List

by Gerry Herbert

There are a few tips I've discovered since having my urostomy that I'm hoping to be of help to others. When changing my appliance I learned the hard way that my stoma might squirt when I was not in the shower or standing over the sink. Needless to say that was a problem. I looked for and found a solution that works well for me.

I purchase paper towels that are a "select-a-size" and take the smaller half sheet, fold it up several times to make approximately a 1" square and hold it over my stoma whenever moving around in unprotected territory. I make three of these sheets and that works well to collect any unwanted output while changing.

To make my skin perfectly dry before applying a skin barrier wafer, instead of using a hair dryer, I use a small 3" battery operated soft plastic bladed fan purchased at Walmart for just a few dollars. I prefer it to a hair dryer as it uses two AA's and will work without needing to be plugged in. It's tiny and pushes a whole lot of air giving me a fast drying time. The blades are so soft that there is no danger of injury if it accidentally touches the skin.

Using a Night Drainage ConvaTec Bottle is essential for a good night's sleep. However the tubing I used from the pouch to the collection container tended to kink and pinch shut. To solve this challenge I purchased some clear hosing from Lowes which has the same 5/16" inner diameter as my ConvaTec hose but has a 7/16" outer diameter which prevents pinching or kinking. I also use hot water from the tap on the fitting when making the hose change to make the hose easier to remove.

Washing out the night collection bottle keeps it odorless and clean. In the morning I swish it out with water mixed with 2 tablespoons each of vinegar and Clorox bleach. After swishing with this solution I again rinse with clear water. I hold the rubber cap in place while cleaning and also run some of the water mix through the hose to clean it also. This keeps the bottle clean and odorless. At night I add an inch or so of water for ballast plus a splash of vinegar. My current bottle has lasted a year and still has no problems.

Again hoping these few hints may be of help to my fellow urostomates and may we all live long and prosper.

We Get Really Important Mail



Hello Wendy,

I just wanted to check in and say hello and possibly help someone out who has Colitis, Pouchitis or IBD. I have some good news to report.

We haven't spoken since I had my J-Pouch surgery. To be honest, this is partly because you "warned" me not to get that operation and I have had a lot of problems with my recovery, and I didn't want to hear you say "I told you so".

I have suffered with extreme Pouchitis ever since I was reconnected about 2 years ago. My doctor had put me on several types of antibiotics which only worked temporarily. In many ways the Pouchitis is more painful and life altering than the Colitis was. This being said, I had severe dysplasia and was told by several gastroenterologists and surgeons that a full colectomy was needed. I now also have nerves that have never awakened in my lower abdomen and sexual area, and I even have neuropathy in my feet due to extended use of the anti-biotic Flagyl. I have no way to release gas (very painful) and need to use a toilet every one to two hours on average. This is not the life I was led to believe I would have by the doctors, post surgery.

Even still, I play very physically interactive basketball, I work out at the gym where I am often naked in a locker room, and I am glad to have an internal

pouch. Perhaps vanity comes into my decision as well. 1041

Although I still have many dreadful issues (“sharting” while sleeping, ED, etc.), my Gastroenterologist in Florida had recommended a specific pro-biotic for me that is actually helping a lot! I am going to the gym almost every day, getting stronger, and able to function fairly normally. And although I can only go a maximum of about 2 hours without a bathroom evacuation, it’s at-least controlled. When I’ve tried switching to other pro-biotics I get very sick after a few weeks, so this stuff is definitely special. I wanted you to know about this product (VSL#3) because it is natural and side effect free and you may be able to help others who also suffer with Pouchitis like I have. Below is a letter I wrote about the VSL#3 to my mom. It explains more about it. I hope you and your family are well. Thanks for all you did to try and help me... If you feel this information is worth sharing you have my blessing to create an article for your newsletter.

Dear Mom, VSL#3 is the pro-biotic that I told you about that has been helping me. It was recommended by my gastroenterologist. It is the only pro-biotic that has been scientifically studied and proven to manage ibd, colitis and pouchitis. I get the powder packets (lemon flavored - it’s mild flavored and tastes good). I shake it up (mix it) in a small covered bottle with an inch of water. I take 3 packets a day (a high dose), morning, mid-day and bedtime. Each box contains 30 packets and each packet contains 250 billion living bacteria. I have severe pouchitis which I’m told is the hardest of all the diseases to control, so I need a very high dose. It’s a natural product and there are no ill side effects. I read online, that if one acquires a doctor’s prescription for the VSL#3DS (double strength), there are some insurance companies that will cover the cost, but mine (Humana) won’t. I order at least two packets at a time depending on my finances (a 20 day supply for me is \$164) because it comes in a eco-unfriendly styrofoam cooler with plastic ice packs, and I want to reduce my packaging waste. It is freeze dried and shipped from California overnight mail (a big reason why it is fairly costly) and needs to be kept refrigerated. I believe it can only be ordered on Monday or Tuesday.

I order it online at: <http://www.vsl3.com/order.asp>
SIGMA TAU PHARMACEUTICALS 301-948-

Recently I took the suggestion of a woman working in the “medicine” section of Whole Foods and tried switching to a different type of Probiotic to see if I could save money. Unfortunately, after 2-3 weeks I got extremely sick. I was bedridden and lost 8 pounds in just a couple of weeks. I went back on the VSL#3 and within a week I started to feel better again. Although it’s costly, I cannot live without it, and it’s similar in price to most drugs. I am grateful to have a natural product that actually works and allows me to live a productive life.

Sincerely,
Ken Fleischer

Editor’s Note: I’m so sorry you’ve had so many issues and challenges to face. I will indeed use your email for an article in the *Broward Beacon*. Thanks so much for giving me permission to do so. I am sure your experiences and insights will be a real blessing to others.



Thank You from our Beloved Amparo Cano CWOON

Wendy and all my friends at BOA,
I would like to write a small letter directed to BOA thanking all of you for the honor you have given me. I consider this national nomination for Nurse of the Year as the most important recognition a nurse can achieve ever! Fondly, *Amparo*

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Swimming.... Back In The Pool!

Edited by B. Brewer, UOAA Update 7/2012



Swimming is an excellent exercise and activity you can enjoy with family and friends. So, why are so many of us afraid to get back into the water? Here are some of our issues and solutions.

I'm afraid that my pouch will leak or come off while I'm in the pool. This is by far everyone's number one concern. The thing to remember is that your pouching system is designed to be leak-free and water-proof, and your wafer adhesive actually gets stronger in water. As long as your seal is strong and intact, strap on your swim fins and jump in. Check out these tips:

1. Don't go swimming immediately after you have put on a new pouching system.

2. Make sure your pouch is empty.

3. Picture framing your wafer with water-proof tape really, really isn't necessary, but may give you the extra confidence you need.

4. Avoid wearing pouches with filters in the pool. Water may get into the pouch through the filter. Filters may become ineffective after they are wet.

I'm concerned that people will be able to see my pouching system under my swimsuit. Dark colored suits with a busy pattern will camouflage your pouch better than light colors like white or yellow, which can become almost transparent when wet. Consider the following tips:

1. Women, choose a suit with a small, well-placed

ruffle or skirt.

2. Men, choose a swimsuit with a higher cut waist or longer legs. Add a lycra or spandex undergarment. Consider a tank top to cover any scars and/or a waist high stoma placement.

3. Colostomates who irrigate may wish to wear a smaller, non-drainable pouch.

I'm embarrassed about changing into/out of my swimsuit in the locker room and people noticing my ostomy pouch. If you are a little modest, try to find a spot that is out of the way or a time that it is less crowded. Some tips follow:

1. You may wish to change and towel off in a convenient bathroom stall.

2. Put on a dry, oversized shirt as a cover-up while you change.

3. A dry suit is easier to take off than a wet one. Relax by the side of the pool with a good book or a talkative friend before heading for the locker room.

4. Wear your swimsuit under a jogging suit/sweat pants and don't worry about changing at all.

What about using the hot tub or Jacuzzi? What about snorkeling or scuba diving? Go ahead. Again, as long as your pouch seal is good and your pouch is empty you should have no problems with your ostomy.

General Tips:

- Take it slow the first time out. Save those strenuous swims and dives until later.

- Always leave a little air in pouch, to permit stoma drainage to fall down into the pouch.

- When sun bathing, take a magazine or book to the beach or pool. Lay it open over your pouch to protect your pouching system (wafer) from the heat of the sun.

- To build confidence, test your pouching system in the bathtub and soak for a few minutes.

- Don't talk about your ostomy surgery at the community pool. If asked, talk in private.

If You Irrigate...

Edited by B. Brewer, UOAA Update 7/2012

- Allowing too much water to enter the stoma too quickly may allow a bit too much pressure to develop. This may cause a sudden evacuation of waste but can leave much of the feces still in the lower part of the

If You Irrigate *continued from page 9*

colon, along with most if the water. Periodic evacuation may follow over the next hour. This is not diarrhea, but simply a delayed emptying of the colon.

- Do not irrigate when having a bout of diarrhea.
- Pain meds and tranquilizers can make the colon lazy and can be the cause of incomplete evacuation.
- Try adding a cup of buttermilk to the irrigation water to decrease unpleasant odor.



UOAA National Conference

August 7–10, 2013

The 2013 UOAA National Conference will be held at the Hyatt Regency hotel in Jacksonville FL. UOAA rotates what part of the country they host their biannual conferences so it will be a very long time before we will be able to attend so close to home. Please don't miss this exciting opportunity to be with hundreds of ostomates from all over the country as well as abroad. At Reno NV there were ostomates attending all the way from New Zealand!

The Hyatt is a beautiful venue for our 2013 conference and our Planning Committee (of which I am a member) is in the process of developing a wonderful experience for all who attend. We have a great line up of workshops, speakers and events that will prove educational and entertaining. Ask anyone who has attended one of our conferences and they'll all tell you about the lasting friendships that were made and the wonderful feeling of being part of a group that offers caring support and education to the os-

tomy community. Be the "U" in UOAA and join us all in Jacksonville.

Editor's Note: If possible I'll be attending a National Conference planning meeting in Jacksonville this Aug. 22nd through 24th and then the UOAA SE Leadership Conference with forty other chapter volunteers through the 26th. Arthur Kravitz, President of UOAA's South Palm Beach County Chapter will also be there and I truly looking forward to being with Arthur and brushing up on my volunteer skills. Our Board was kind enough to approve helping me with some of the expenses. Sincere thanks for always being there for me. I'll be updating you on the adventure. I'm going by train so I'll be able to report back to you on that experience and if it's a go, we all should start making plans now to be on the same train together on our way to Jacksonville in 2013! Now wouldn't that be fun.



The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains inspiration, education and information including new products, medical advice, management techniques, personal stories - it's all here. Published each March, June, September and December. Subscriptions directly fund the non-profit United Ostomy Associations of America. **Subscribe Today!**

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