

Volume XLII Issue No. 5

May 2012



# Broward Beacon



**Next Meetings: Sunday, June 3rd 1:00 p.m.**

**Summer Break: 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.

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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



This is a difficult message for me to write this month. First let me share some encouraging meeting details. A new friend of BOA has generously donated a luncheon for our September meeting catered by Subway. Wow! How kind. So be sure to put September 2nd on your calendar now. We're also having a wonderful ostomy nurse at that same meeting who will be speaking on, "What Not To Put Up With". Such a great topic.

BOA takes a summer break so the next issue of the *Broward Beacon* will not arrive until mid August nor will we be holding meetings in July and August. All are volunteers are such hard working, wonderful friends. It's good for all of them to take a well deserved short sabbatical. However, please be reassured that our 24 hour hotline always remains open and available.

Now for the difficult news. I'll share with you an email that my sister Pam sent out to her acquaintances which explains all. "Hello! I know it has been way too long since I have written, and I apologize. A lot has happened in the past few months, and I knew you would want to know about it.

The reason I have not been writing is because of

my daughter Samantha. In short, her cancer came back to her neck.

It all happened over the past few months, and we had thought all had been removed a year ago. But her yearly PET Scan showed a large tumor in her neck again. Sammy just came home from the hospital where she had a twelve hour surgical procedure to remove a stage 4 cancer and reconstruct her neck, throat, and tongue. It was all very frightening and she was in an Intensive Care Unit with a tracheotomy for over five days.

After she recovers from this major surgery, she will need to have radiation and chemotherapy to hopefully keep this from happening again.

Sammy, as ever, is optimistic, a strong trooper and does everything she can to speed up her recovery. She is now at home and learning to swallow again. She is able to talk, which the doctors say is unbelievable after the reconstruction of her tongue, so you see she is a fighter! This will all take several months, and I just thought you would like to know. Love, Pam"

Pam, an ostomate herself, spoke at our April meeting and you all saw images of her beautiful daughter on their seven year voyage around the world. Samantha is 35 years old now and has a truly beautiful 16 month old daughter, but then again, I'm very prejudiced.

Please join me in prayers and good wishes both for my sister Pam and my niece Samantha on this new journey. We're all attempting to think of it as a rough passage on their sailboat with a peaceful, healthy and inviting landfall just ahead.

Thank you for all your love,

A handwritten signature in cursive script that reads "Wendy".

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## B.O.A. MINUTES May 6th, 2012

President Wendy Lueder opened the meeting at 1:30 p.m. which was attended by more than 50 members and guests. The Ostomate's Prayer was read by Mary Lou and first time guests Betty, Jack, Rose, and Jane were welcomed. Wendy pointed out the encouraging news that a scientific study by Duke University

concluded, that the longer a person has had an ostomy, the better their quality of life.

Eula and Lea were introduced; our Certified Wound, Ostomy and Continence Nurses who volunteer their time to attend our meetings out of the goodness of their hearts. Lea is also looking into the details of sending L.T. to Youth Rally again this year. The Broward Ostomy Association enabled him to go last year and furnished L.T. with a refurbished computer donated by Broward College. Many members

*continued on page 4*

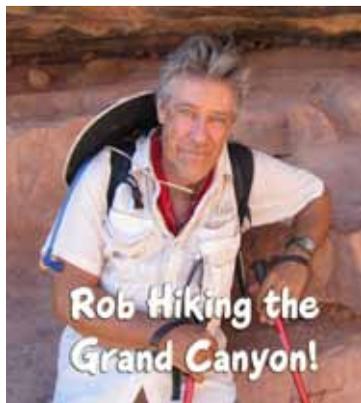
# Next Meetings:

**Sunday, June 3rd, 2012**

**Refreshments, 1:00 p.m.**

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

**Meeting: 1:30 p.m.**



As I have written before, “to know him is to love him”. We are delighted to have as our June guest speaker Mr. Rob Seaman. I’ve known Rob for more years than I can remember and he is the dearest company rep out there. Rob

will update us in his charming and approachable way on all that’s going on at ConvaTec which is one of the few companies that manufactures a comprehensive line of ostomy products.

Come and learn about their full product line. Having well-fitting, well functioning ostomy equipment is one of our highest priorities. Don’t miss this opportunity to learn the latest about their ostomy line. Requests for free samples are always honored by ConvaTec and you owe it to yourself to discover whether one of their products is just right for you. Looking forward to seeing you there.

L.T. will also be joining us and will give us an update on his new adoptive family in Pittsburgh, PA. As L.T. will be moving out of state immediately after camp, please don’t miss the opportunity to wish him a very fond farewell and if you like, make a small donation toward his spending money for camp which, thanks to your generosity, he will be attending July 9th through the 14th at the University of Colorado, Boulder. We are so excited and happy about L.T.’s adoption. Family is what it’s all about!

## 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. June 3rd. Summer Break, September 2nd, October 7th, November 4th and December. 2nd. Detailed meeting information including a wonderful map can always be viewed on our website [www.browardostomy.org](http://www.browardostomy.org).

## Minutes *continued from page 3*

have donated funds to cover L.T.’s camp expenses but we especially thank one of our members who with their extremely generous donation put us over the top to pay L.T.’s camp expenses for 2012.

Leroy was recognized for catering last December’s delicious Banquet, and providing a wonderful spread of sandwiches for the April meeting. Helen Gins-



**L.T. and friend at Youth Rally 2011**

*continued on page 6*



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## Minutes *continued from page 4*

burg continues to chair the telephone committee, and if you would like to have telephone reminders of upcoming meetings let her know.

The Fourth United Ostomy Associations of America, Inc. (UOAA) National Conference will convene in Jacksonville, FL on August 7th thru 10th, 2013. These conferences are a life-changing events and Wendy has attended many. Everyone is encouraged to save up and make reservations to attend this as they are rarely this close to our area. Arthur Gilbert provided information that Amtrak runs from Fort Lauderdale to Jacksonville in just under 8 hours, and a round trip reserved in advance for two currently costs \$116. More details on the Conference are coming soon.

In other news, Wendy showed necklaces she designed that were featured in *Bead & Button* magazine. A new necklace is also being scheduled for publication in the February 2013 issue of *Beadwork* magazine.

Vice President and Program Chairperson Amy introduced Mr. John Chickey, our customer service representative for Hollister Ostomy Care products who has just moved from Illinois to Florida. He has worked as a patient coordinator in the mid-Atlantic region for five years and works with Hollister's Secure Start Program. He has attended many support group meetings around the country and commented that we have one of the largest attended groups he's seen. John will be the company's Ostomy Specialist in South Florida. His Fiancée works for American Cancer Society and their two vocations often cross paths.

Hollister was started over ninety years ago by a man named John Dickinson Schneider. The company started as a printing company in Chicago, but evolved to develop medical products for a variety of needs. An example of their early products is the patient identification band that helped set the standard for patient identification in U.S. hospitals. Hollister now has an international presence with five major manufacturing centers.

Through Hollister's Secure Start Program, John provides information on products and services

to people with ostomies. The program works with nurses and patients throughout the country. Secure Start has both a patient and clinical advisory board. Patient kits are provided through this program that contain educational brochures and sample products. There are also DVDs for both current ostomates and for those preparing for surgery.

John demonstrated a number of Hollister's products and distributed product catalogs. For more information call the Hollister Consumer Hotline at 1-800-740-8999 Monday through Friday, 8 a.m. to 5 p.m. central time. Certified Wound, Continence and Ostomy Nurses are on staff. Catalogs and free samples of products can be sent to your home. Their Internet site is [www.hollister.com](http://www.hollister.com). Much information has been recently updated.

John ended his program with a contest of Hollister trivia for prizes that he brought. In his closing statement he said "We all have a responsibility to help and educate others who have this surgery." Wendy awarded John her famous homemade fudge brownies and a certificate of appreciation for speaking to our group.

In adjourning the meeting at 2:37, Wendy pointed out that samples of the 3M™ Kind Removal Silicone Tape, mentioned on page 7 of the May issue of the *Broward Beacon*, were distributed on each table for members to take and try out. The next meeting will be June 3rd, followed by summer recess until September when the topic will be "What Not to Put Up With." See you in June.

Respectfully submitted,



Bill Wilson  
Recording Secretary



## Traveling With An Ostomy

*from Stuart Online and other Ostomy groups*

Your ostomy should not prevent you from traveling. However, you should pay attention to the following points to avoid problems:

1. Some recommend taking 3 times the number

of supplies. This allows for defective products, prolonged athletic activities especially in hot weather, flight delays, and traveler's diarrhea.

2. Pack products in your carry-on bag. A few items can be placed in your check-in bag and your companion's bags.

3. Pre-cut your products so you will not need scissors in your carry-on bag, although scissors with less than a 4"-long blade and with blunt tips are now acceptable.

4. Make a note of the size, order number, and manufacturer of your supplier, and the supplier's phone number—you may need to purchase items while away from home. In foreign countries, check with the local pharmacies that may be able to provide you with substitute supplies, if necessary.

5. Book an aisle seat when making your reservations, for easier access to the toilet.

6. To counter dehydration (and jet lag); drink a glass of water or fruit juice every hour.

7. For those who use closed pouches, order drainable bags which will make coping with possible diarrhea a little easier.

Barbara Kupfer's book, *Yes We Can!*, is one of the best current resources available for advice on traveling with an ostomy. Traveling was always a part of her life, and after surgery for colon cancer, she was determined to continue to see the world. She also realized that if she was asking questions, then other people were also looking for answers. Besides her travel advice, her book also offers the opportunity to read the stories of others who travel.

## Summer Hints...

### Get back into the swim of things!

*Edited by B. Brewer, UOAA Update May 2012*

- For extra security during swimming and water sports, consider using extra tape around the barrier. This is called picture framing.

- Select a bathing suit made of textured or dark-colored materials that will better hide the outlines of the pouch. Some women prefer bathing suits with skirts and some men prefer boxer-style trunks, but snug-fitting suits can be worn.

- A light-weight 2-way stretch garment can be

worn under a swim suit for extra support and flatness. And gentlemen, a pair of jockey shorts should do the same for you.

- Take precautions against sunburn. A very bad sunburn can result in diarrhea and sometimes vomiting, thus depleting electrolytes.

- Monilia is a common summer problem. This raised, itchy, red rash on the peristomal skin is uncomfortable and keeps the pouches from holding well. If you suspect a monilia rash, check with your doctor and/or to secure a prescription for anti-monilia powder. This may require an office visit for a consultation and visual examination.

- If plastic against your skin is uncomfortable or causes a heat rash, you should purchase your pouches with the cloth-like covering or consider purchasing a pouch cover.



## A Patient's Guide to Managing a Short Bowel/Gut

*Written by a GI Dietician*

Living with short bowel syndrome (SBS) can be challenging. Fortunately, there are things you can do to help the GI tract work more effectively. Visit [www.shortbowelsupport.com](http://www.shortbowelsupport.com) to register for information and receive your complimentary copy of *A Patient's Guide to Managing Short Bowel*, created by Carol Rees Parrish, MS, RD.

This book was written to help people living with short bowel syndrome (SBS) understand the workings of the gastrointestinal (GI) tract and how to maximize what is left. This book can empower patients and their families to take charge of their SBS.

## How to Change Your Appliance

*by Wendy Lueder*

**Editor's Note:** The BOA has two forms of their newsletter. One form is published nine times per year

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and contains time sensitive information. The other form we've been calling our "timeless issue" which we give to first time visitors and telephone inquirers. This issue has no information that may change over time and the contents were chosen to cover those topics of greatest importance to ostomates.

The following article is from our timeless issue and contains fundamental information for all ostomates. The tips in this article have been gleaned from over forty years of living with an ostomy. My hope is that even if just one person is helped by presenting this information, then all is worth it.

If you feel overwhelmed by changing your appliance, please know that your feelings of anxiety will diminish over time. I know it can be difficult at first but it will become more routine with practice. Knowing just what you're going to do can be helpful so here are some basic guidelines that you may wish to use.

1. To start, wash your hands!

2. Set out your equipment within easy reach on your bathroom counter top. You will need: an old bath towel on the floor and Kleenex tissues (without any lotion!) to catch any unwanted output while changing; plastic bags for clean-up; a washcloth if you don't shower; clean bath towel; pencil and stoma measuring guide; scissors or x-acto knife if you don't use the new "moldable" skin barrier wafers; a skin barrier wafer; Stomahesive or HolliHesive paste or product such as Eakin Cohesive Seals (preferred by this writer) a new pouch; a tail closure if you use a drainable pouch that doesn't have the built-in Velcro closure ; hair dryer and finally, a swivel make-up mirror.

3. Empty your pouch as normal. **DO NOT** rinse your pouch out when emptying. This only reduces adhesion. If you get this advice, ignore it. Rinsing out pouches is an obsolete suggestion that is totally bothersome and no longer valid for modern ostomy equipment. Empty your pouch while sitting comfortably and normally on the toilet. Put some toilet paper in the bowl first to avoid any splashing. If you use a tail clip, carry an extra one with you in case you accidentally flush yours down the toilet

4. While holding a corner of the tape that holds

your appliance to your body, gently push your skin in toward your body to remove the appliance. Pushing your skin inward is far less harsh on it than if you pull the appliance off and away. Try it and feel the difference. You only need to use an adhesive remover if: A) you have worn the skin barrier wafer a very short time and the adhesion is still very strong and/or B) your skin is irritated or tender and can be easily damaged. I personally prefer the spray adhesive removers as they leave less residue. However, I only use them if I have worn the barrier for less than two days between changes.

5. Put the old pouch, wafer and other waste (not the tail clip!) into a plastic bag for disposal. Sealable sandwich bags work great. My favorite product is Ostaway x-bag which is a black, opaque, leak-proof, odor-proof zip-lock bag made just for this purpose. See [www.bagitaway.com](http://www.bagitaway.com) or call 1-800-774-6097 (Mon-Fri 9 a.m. to 5 p.m. Eastern).

6. Clean the skin around the stoma with a washcloth and warm water or by getting into the shower and using your hands. Be gentle. Do not use scented or cream soaps as they will diminish adhesion of your skin barrier. Any waste coming out of the stoma will merely wash down the drain.

7. Pat your skin dry with Kleenex and for best results use a hair-dryer on low setting to complete the job. The cleaner and dryer your skin is the better your skin barrier will adhere.

Measure your stoma with a measuring guide (usually supplied in the box with your skin barrier wafers) using the make-up mirror placed on the counter top to get a better look. This is especially important if your surgery is recent as your stoma will become smaller over a period of months.

For all Skin Barriers except StomaHesive Wafers measure right up next to the stoma. For StomaHesive Wafers add an eighth of an inch space between the stoma and the wafer hole. Only this brand of wafer is "stiff" and could damage your stoma if it is too close. All other types of skin barrier wafers are more flexible and won't damage the stoma if placed right up next to it. If your stoma is oval take two measurements, one each of the larger and smaller diameters.

8. Trace the correct size and shape onto the back

## How to Change *continued from page 9*

of the wafer with the starter hole in the middle. Cut out the hole either with your scissors or more easily by using an x-acto knife.

There are new moldable skin barrier wafers that you do not need to cut but merely manipulate to create the correct size opening. This is especially helpful if your stoma is oval and is highly recommended by this writer. Follow the manufacturer's directions to create the perfect size opening for your unique stoma.

9. If you use paste, peel the paper from the wafer and apply the paste only by the width of the tubes opening around the cut circle in the wafer. Allow alcohol to evaporate for approximately thirty seconds. Unfortunately paste is poorly named. Paste is really merely caulking and has no adhesive property.

If greater protection is needed than paste can afford (such as for ileostomates who have a caustic output), try using an Eakin Cohesive Seal instead of paste. Eakin, which has the consistency of silly putty, lasts far longer and will not wash away from heavy output. However, this is an expensive product (available through ConvaTec) but it works.

Small dabs of paste or small pieces of Eakin Seals are great to fill any dimples in your skin that you may have. The flatter the surface of your skin around the stoma, the better the seal.

10. While leaning slightly backwards to smooth out your skin, remove paper backing from the skin barrier and apply it slowly and carefully over the stoma.

Use the magnifying side of your mirror to see that you are correctly setting it in place. Remove the paper backing from the surrounding tape and smooth it out on your skin being careful not to create any wrinkles as they may later dig into your skin.

11. If you use a two-piece system, snap the new pouch onto the wafer. Never tug down on the appliance to see if it is secure. Instead, feel with your finger all around the "Tupperware" closure to make sure the pouch and wafer are as close to each other as can be. If you detect any space, push the pouch toward your body until you feel it close the gap. You may hear a series of clicks as you apply the pouch.

12. If you use a tail clip, apply now. Hold your appliance in place with your hand for a full five min-

utes to ensure a secure seal. All skin adhesives are more effective if held in place after first application as the heat from your hand improves adhesion.

If your stoma is flush to your skin, use a skin barrier wafer with built-in convexity. The convexity will gently push the skin toward your body around the stoma giving it some extra length. When the stoma thus protrudes a bit more, its output goes more easily into the pouch.

Don't wear a belt to hold your appliance on tighter unless directed by your health care professional. The new adhesives and skin barrier wafers stay put well for days. Belts are uncomfortable and usually unneeded.

Some bleeding is normal when touching your stoma, but report any unusual color, size, shape, or bleeding to your Ostomy nurse. Try different products. Call your Ostomy nurse or ostomy supply companies and ask for free samples. You may have to shop around to find products that leave you feeling comfortable and secure. You should be no more aware of your appliance than you are of your underwear. Always follow any special instructions provided by your health care professional as they know your specific situation better than any general guidelines an article such as this could provide

If your abdomen is very hairy, you may want to gently shave off the hair under your skin barrier wafer. Be careful not to cut or damage your skin.

These suggestions are gleaned from years of helping ostomates cope and are just that, suggestions. They come from over thirty five years of experience, but are in fact just the input from a layperson. I'm not a nurse, I'm an ostomate. Your health care professionals always know best and you need to follow their advice, not mine.

Bottom line: Your appliance should be comfortable, stay on for at least a few days between changes, odor-free (not odor resistant) and leak extremely rarely. If not, see an ostomy nurse and change your routine until you find the products that work well for you. Studies done at Duke University verify that the longer you've been an ostomate, the better it gets. Problems do diminish with time and experience. You should be able to forget you're an ostomate and get on with doing the things you really enjoy. There's no stopping you.

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## **Broward Ostomy Association Membership**

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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