

Volume XLVIII Issue No. 2

Summer Quarter 2018



Broward Beacon



Meetings: June 3rd: September 2nd ~ 1 p.m.
(Summer Break July & August)

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

Broward Ostomy Association



Our Vision ~ a society where people with ostomies are universally accepted and supported socially, economically, medically and psychologically.

www.browardostomy.org
Chapter Hotline (954) 537-0662

Shedding The Light Of Hope, Help, And Education For Ostomates Through Visitation & Rehabilitation. Published by the *Broward Ostomy Association*, a 501(c)3 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 June at 1:00 P.M. excepting our Holiday Banquet in December which is by reservation only and meeting at 4:30 p.m. All meetings 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 to the right. 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'm so excited to announce the launch of the NEW Miami Ostomy Aftercare Support Group. This is the first meeting of a much-needed Miami Dade group for patients who have had ostomy surgery. Patients, their care-givers, loved ones, and medical professionals are welcome to attend. They will provide support services, resources and reliable, knowledgeable advice. Come, assist in setting the agenda for this new Support Group at its very important first meeting.

Tuesday, May 22, 2018, 6 p.m. to 7:30 p.m. (Mark your calendar for their 2nd meeting on June 26th). Jackson Memorial Hospital, DTC #252 1080 N.W. 19th Street, Miami, FL 33136. Parking garage near entrance, 1st 2 hours free. For more information call 786-580-3928 or email moap@miamioostomyaftercare.org.

Our good friend Hal Spaet spent months of his time and energy making this new group a possibility. We are so grateful for his selfless dedication to help others regain full and active lives after having undergone ostomy surgery. Bless you Hal.



On a less happy note, I'm sad to announce that our beloved Medical Advisory Board member Susan Magri is moving out of the area. As Susan wrote, "I wanted to let you know that I am moving to Virginia in May! I will be working for the University of Virginia Health System, in the wound and ostomy department. I have enjoyed being a part of the BOA. It's a wonderful organization and you are amazing!" And as I replied, "I am so happy for you and so sad for myself and your BOA family of friends. You really understand our mission and are so supportive. This is a huge loss for us. Please stay in touch."

If you haven't renewed membership in our group for 2018, please do it now! Our dues are still only

\$10. You can renew by using the membership form in this newsletter or just bring payment to our next meeting. Your contributions will help us send Miguel to Youth Rally Camp this summer in Boulder CO. I can't think of a more worthy way to allocate our funds.



You often see me in the Main Lobby to assist you getting through the Security Check-in Line. Wonderful Melvina has graciously volunteered to help me out. So next time you need assistance getting past Security, please look for either Melvina or myself to get a security badge without waiting in line. Thank you Melvina!

Please welcome a new supporter of BOA, **Shield HealthCare**. You can view their booster on page 12 of this issue. I was very impressed with the quality of articles their website provides and contacted them to ask permission to reprint some of their materials. They were kind enough to ask how they could support our chapter and the monies they're providing BOA will help underwrite approximately a third of the cost to send Miguel to Youth Rally Camp. Julie of **Ostomate Inc.** (see page 5) has also been an immense financial supporter of sending Miguel to camp. Thank you **Shield** and thank you Julie for your generosity and kindness. It's a real pleasure working with you.

I am amazed and full of gratitude for the high spirit of giving by BOA members and friends. Our volunteers are what enable BOA to thrive. Have you noticed we don't ask you for financial support? That is because you are oh so generous and give without solicitation. Not only do you give funds but you give of your precious treasure of time and talent. I fear naming you all individually as I probably would accidentally forget someone who is so good to us. So may I just say, you are loved, you are appreciated and I am so profoundly grateful.

Fondly, *Wendy*

Next Meetings:

Sunday June 3rd, 2018

Summer Break

Sunday Sept. 2nd ~ 1:00 pm

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

Speakers: 1:30



June 3rd, 2018

Ask Our Experts: Our expert volunteer team of CWOCNs (Certified Wound, Ostomy and Continence Nurses) will share the most frequent concerns they encounter as well as some uncommon cases. They will also answer questions from members and guests.

Upon entering the meeting, attendees will have an opportunity to write a question for the panel on an index card. Questions will also be answered during the meeting as they arise.

We are most grateful for our dedicated CWOCN specialists who give so generously of their time and knowledge. They are the wind beneath our wings in so many ways as facilitators, liaisons and medical advisors, bringing us the best of the area's hospitals and professionals.

Amparo, Ana, Patty, Lea, Eula, Debbie, (not shown) Glicerio and Carlos, we cannot thank you enough!

Becoming a CWOCN is in fact a big deal. The WOCN Certification Board (WOCNCB) began certifying nurses in 1978 as a way to recognize and differentiate the value of expert nurses from those at an entry level. While a nurse who is not board certified may possess basic entry-level skills,

he or she may not have the specialized skills and experience to adequately provide expert care. Board certification ensures that a nurse is knowledgeable and well qualified to provide specialized care to meet patients' wound, ostomy, continence, and foot care needs. Certification must be re-established every five (5) years.

Just because a nurse says that they are an ostomy nurse doesn't necessarily mean that they have the extra training. Be sure to ask if they are in fact a CWOCN.

September 2nd, 2018



Once again our Focus Group Round Table discussions welcome members to share personally their challenges and their successes. This is our time to learn from and to encourage one another. The majority have expressed value in hearing about the experiences of others in a safe, casual and open forum.

No one needs to feel the pressure to speak. Often listening is a great comfort to know we are not alone. Index cards will also be available at the beginning of the meeting as an alternate way to communicate questions and concerns.

Some participants have had surgery as recently as within a matter of weeks and others first adjusted to an ostomy almost 50 years ago ! With this range of experience, the resulting impact is often one of hope and inspiration

Each group: Colostomy, Ileostomy, Urostomy and Family and Caregivers will be guided by a WOCN facilitator. At the end of the meeting we will share some of the significant points made in each group.

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BOA Meeting Dates

Please, if you are as forgetful as I am, take a moment to mark your calendars now for our upcoming meeting dates. This is especially important since the *Broward Beacon* is now published quarterly.

Our spring 2018 meeting will all be held **June 3rd**. We then take a summer break in July and August and start up again **September 2nd, October 7th, November 4th**. Our Holiday Sit-Down Dinner Banquet catered by our beloved member Leroy is being held by reservation only on **December 2nd!** All meetings are held in the Main Auditorium.

Minutes General Meeting February 4th, 2018

The meeting was called to order at 1:30 pm in Memorial Regional Hospital's Main Auditorium in Hollywood, Florida by Wendy Lueder, President. The Ostomate's Prayer was read by Larry. First time visitors were greeted: Linda, Emily and Ingrid. Emma was thanked for providing the refreshments.

Attendees were reminded of the Annual Board Meeting scheduled for after the regular meeting March 4. Everyone is invited to give their input on important decisions. The April meeting will be canceled due to conflicting with Easter. The May and June meetings will still be held in the auditorium. It was previously thought that we would have to be relocated for those two months.

Julie from Ostomy Inc. was gracious enough to

provide a donation in honor of her loving mother who was the first ostomy nurse in Broward County. Julie along with her mother have provided assistance to ostomates throughout these many years. Thank you so much Julie.

The Weston Support Group will have its inaugural meeting this February 21 at Cleveland Clinic Hospital. Debbie motioned to give a gift of some money to help them get started. This was seconded by Jeannette. Lynn Wolfson, President of the Weston group, wanted to share that this is a sister chapter of BOA and that all are welcome to attend both meetings.

Ostomy Chic

Leah shared a video that was originally presented at the 2017 WOCN National Conference in Salt Lake City by Leanne Richbourg on pouch concealment strategies. Leanne is from Duke University and gave permission for this to be shared. The video consisted of ostomates demonstrating how they manage concealing their pouches using inexpensive and easily available products (from places like Walmart and Target). Spanx and spanx-like products purchased a size larger than what one normally wears seemed to be a basic start especially when coupled with a loose-fitting top. These are tighter than a pantie but looser than a girdle.

OSTOMY Secrets also sells apparel but it was noted that sometimes the pockets on those products do not match up with the pouches. They do however carry men's products as well.

Some ladies preferred boy leg panties, "Granny Panties", or bikini panties. Some people wear two pairs of underwear and put the pouch between them. There are post-partum panties available as well – it was suggested to try these with the presence of a hernia. There are long, shaping camisoles on the market from a variety of retailers. Both men and women liked using maternity wraps or bands which are also available at Target and Walmart. Tennis shorts and bike shorts are useful but can be costly. One person recommended Under Where available at Zulilly on line – she used this for her hernia.

Other hints included:

- Patterned shirts
- Asymmetrical shirts, dresses, tunics
- Pants and jeans with elastic inserts in waistbands
 - Tunic tops with stretchy jeans and leggings
 - Wearing clothes in layers
 - Maternity jeans and maternity tees with a flare on the end
 - Tops that gather in the front or have pleats in the front
 - Dark colors
 - Men's boxer briefs if nylons or tights or too hot under dresses
 - Yoga pants that can be folded up or down at the belly area
 - Spanx slip
 - Suspensiers for men
 - Stoma guards available from Stomaplex, Freedom Guard, Stoma Armor, Ostomy Resolutions, or Stealthbelt

Some ostomates said they wear their pouch sideways especially when wearing a bathing suit.

There are many websites and You Tube videos to help with resources and ideas:

- Vegan Ostomy
- Team Rebecca
- The Front Butt You Tube
- Stephanie Hughes
- Crohnie Bologna IBD

The meeting concluded at 2:30.

Minutes General Meeting

March 4, 2018

Wendy Lueder, President of BOA, called the meeting to order at 1:30 p.m. in the Main Auditorium at Memorial Regional Hospital in Hollywood, Florida. The Ostomate's Prayer was read by Larry.

First time attendees were greeted: Charles, Jorge, and Bob who is here in behalf of his wife. The co-chairs for first time visitors are Bonnie for the ladies and Bob for the gentlemen.

Amy introduced the presenter today, John Chickey from Hollister. John has worked with Hollister for more than ten years.

Ceramide and Hollister: The Benefits

He informed us that Hollister is focusing its research and design department to improve the quality of life for ostomates by infusing barriers with ceramide to promote healthy peristomal skin (skin around and next to the stoma).

John showed us a video which is accessible on YouTube by Ray, a NASCAR race driver. Ray had a history of abdominal cramping and pain along with passing blood in his stool. He was diagnosed with Crohn's Disease. In 2015, he was diagnosed with having precancerous cells at which time he was encouraged to have an ostomy created to prevent further problems associated with colon cancer. Ray was concerned about his new ileostomy and how he could continue to race. He gets strapped down in the driver's seat in a hot car.

Would his pouch continue to stick without skin problems in this environment? The answer was yes – with ceramide infused wafers he has had no problems. As a matter of fact, Ray said that he has done more in the last two years since his ileostomy than he did the fifteen years prior to that with the disease without an ostomy. His four-year-old daughter helps him with the pouches and always makes sure his pouch is okay when she climbs onto his lap.

Ceramide is a natural component of human skin. It is found in the epidermis (the outer layer of skin) holding the cells together leading to a waterproof barrier for the skin. The ongoing use of historical skin barriers eventually leads to thickened skin, inflammatory cell infiltration, mechanical skin trauma, and maceration/peristomal itching and pain along with pouch leakage diminishes the quality of life of ostomates. In a study John mentioned 75% of ostomates stated they have had some kind of peristomal skin complication but only one of five actually sought treatment for this. Ceramide is not only a preventive intervention but also treats the above complaints.

CeraPlus is a barrier infused with ceramide. When the ceramide integrates into the peristomal skin, the peristomal skin becomes more resilient and less apt to break down when all those forces we discussed above come into play. It enhances adhesion/tack,

absorption, and erosion resistance.

John shared the results of “The Advocate Study” a Randomized Controlled Clinical Trial that was Double Blinded and Adaptive. The study showed that *CeraPlus* decreased incidence of peristomal skin complication’s and decreased cost associated with peristomal skin complications. This is the first and only study with this amount of statistical significance that has ever been done in the ostomy world. The study was done in the U.S., Canada, and Europe which included 153 adults in 25 different sites. The results were published in the January/February 2018 issue of the (WOCN) Journal of Wound, Ostomy, and Continence Nursing. The co- author of WOCN actually recommends that the nurses should read this study. His notes are in the issue.

The study was called the ADVOCATE study which is an acronym for A randomized controlled trial determining the Variances in Ostomy skin Conditions and the Economic impact. During the study it was found that peristomal skin complications were significantly more likely to resolve in a 4-week period with the use of *CeraPlus* skin barriers leading to improved patient satisfaction. This also affects the economic burden of having to replace the pouch and/or barrier frequently as well as reduced cost involved of treating the peristomal skin. Hollister compared their *CeraPlus* barrier with their barriers without ceramide.

Question: Where were the statistics derived about how many ostomates seek help treating peristomal complications? Answer: Janice Colwell RN, MS, CWOCN, from the University of Chicago Medicine who is a nationally known speaker and researcher.

John had samples for the attendees. There are multiple different sizes of *CeraPlus* barriers in both one and two piece that are still coming out. There is a soft convex one-piece urostomy pouch with ceramide coming out. He went over Hollister’s *Adapt CeraRings* which are infused with Ceramide and are available in regular and slim. The *CeraRings* are also available in circle convex and oval convex. He also showed us *Adapt* barrier extenders which some people put around the outside of the pouch for extended wear while exercising, etc. He talked

about Hollister’s adhesive remover spray which is very effective against skin stripping and mechanical skin trauma of removing the barrier.

John concluded by reminding everyone of the significance of skin health and how that could affect the quality of life for an ostomate. He also reminded the attendees the importance of being there for one another and helping those who are new to ostomy. Anyone can call Secure Start with any questions or problems as well as to ask for additional samples. Call 888-740-8999. The meeting concluded at 2:30 pm.

Respectfully submitted,



Debbie Walde
Recording Secretary



PROCEDURES THAT CAN BACKFIRE

From Tulsa OK

Normal Wear Time: You shouldn’t wear the appliance until it leaks. The object is to change the appliance before leakage occurs. This way, the skin gets the best protection and care. Three to five days is normal wear time. Some people report seven days, but manufacturers feel that this may be pushing their products to their limits.

Ignoring Skin Problems: All skin problems are easier to manage if they are treated early.

Seat Belts: A seat belt shouldn’t interfere with or damage your stoma. It’s a fact that over 50% of people who’ve died in a motor vehicle accident in the US were not wearing a seat belt. There are products available to protect your stoma such as Stomplex or StomaDome that create a barrier between a seat belt and your stoma. Check them out on the web.

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How to Clean the Skin Around the Stoma

by Laura Cox, Ostomy Lifestyle Specialist
Shield HealthCare



People who manage an ostomy pay special attention to the stoma site and surrounding skin. It's very common to be concerned about skin irritation caused by exposure to stool or urine. With this in mind, the WOCN Society developed a Basic Ostomy Skin Guide to

address typical questions. The guide is designed to help you use products correctly, protect the skin and gently clean and care for the stoma and surrounding skin.

Here are the WOCN's answers to the most commonly asked questions about stoma cleaning and care.

How to Clean the Skin Around the Stoma: To clean the skin around your stoma, all you really need to use is warm water and a washcloth (or good quality paper towels). The use of gauze or gloves is not usually necessary, although you can use them if you feel more comfortable.

For those that prefer to use soap to clean around the stoma, it's best to use a very mild soap. Avoid using soaps and cleansers with oils, perfumes or deodorants since these can sometimes cause skin problems or prevent your skin barrier from sticking.

Rinse the soap off the skin around your stoma very well. Soap residue may keep your skin barrier from sticking and may also cause skin irritation.

If you are using a skin paste, it may be easier to remove the paste before you wet the area. Some people may use adhesive remover. Do not worry if a little bit of paste is left on your skin.

Always dry your skin well before putting on your new pouching system. (Your editor uses a hair dryer)

Do not use alcohol or any other harsh chemicals to clean your skin or stoma. They may irritate your skin.

Do not use baby wipes or towelettes than contain lanolin or other oils, as these can interfere with the skin barrier adhesive and may irritate your skin.

Unless recommended, do not apply powders or creams to the skin around your stoma because they can keep your skin barrier from sticking.

Sometimes you may see a small amount of blood on your cloth. The stoma tissue contains small blood vessels and may bleed a small amount when cleaned. Any bleeding that does not stop should be reported to your health care provider. The stoma has no nerve endings, so you are not able to feel if you are rubbing too hard. For this reason, use a gentle touch when cleaning around the stoma and do not scrub.

The basic rule that applies is not to use too many products on the skin. Do not use adhesive remover if you have skin that tears very easily. If you do use adhesive remover, always wash well with water and mild soap to remove the oily coating on the skin. Then rinse the skin well with water and dry completely.

If you recently had ostomy surgery, it's recommended to measure your stoma once a week for the first six to eight weeks after surgery. Your stoma shrinks while it's healing and you will need to make sure that the opening in the skin barrier is the right size for your stoma. Re-measure your stoma if you experience skin irritation close to your stoma or beneath the skin barrier wafer.

Should you experience painful skin problems or severe irritation around the stoma, please contact your health care provider or WOC Nurse.

Meeting the Right Person

Before having surgery, Brian was nervous that his ostomy would keep him from meeting the right person. Having confided this in a friend, she answered: "Brian, the ostomy won't keep you from meeting the right person. It will keep you from meeting the wrong person."

Brian took that advice to heart. "If someone isn't okay with my ostomy, then they're not okay with my life and they shouldn't be in my life."



Brian Greenberg
Shield HealthCare

Memorial Outpatient Ostomy Clinic

At Memorial Regional Outpatient Ostomy Clinic, their goal is to provide quality care to adults and children who have had ostomies. They offer a variety of care and support including: preoperative and postoperative education on living with a stoma; appliance selection and application; peristomal skin complications and care; dietary counseling; routine stoma care and support for coping with lifestyle modifications. For more information or to make an appointment call 954-265-4512.

South Florida Ostomy Support Group

At Baptist Hospital meeting every third Wednesday of the month from 6-7 pm at the Baptist Health Resource Center, Medical Arts Building, located at 8900 North Kendall Drive, Suite 105, South Miami FL. Summer break July–August. For more Information, call Lourdes Placeres at 786-596-6036.

Coral Springs Support Group

Coral Springs Medical Center’s “Caring & Sharing Support Group” meets on the 4th Wednesday of the month at 5:30 p.m. to 7:00 p.m. For more information and to call and confirm as they do take a summer break, contact Patty Paxton-Alan MSN, ARNP-BC, CWOCN at 954-344-3094.

Miami Ostomy Aftercare Support Group

Tues. May 22, 6 p.m. to 7:30 p.m. (Mark your calendar for our 2nd meeting on June 26th) Jackson Memorial Hospital, DTC #252 1080 N.W. 19th Street, Miami, FL 33136 Parking garage near entrance, 1st 2 hours free. For more information call 786-580-3928 or email moap@miamioostomyaftercare.org



BOA does not endorse any products or methods. Consult with your doctor or Ostomy Nurse before using any products or methods either published in this bulletin, displayed, described, demonstrated or distributed by sample at our meetings or recommended by an association member.



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 quarterly newsletter, the *Broward Beacon*. Please make checks **payable to BOA** and mail to: The Lueders, 2100 S Ocean Dr Apt 16M, Ft Lauderdale Fl 33316-3844. BOA never shares membership information with anyone. We value your privacy. BOA is a 501(c)3 charitable organization.

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Meet Laura Cox, Shield HealthCare ostomy lifestyle specialist. An ostomate since 2011, Laura shares insights and advice on living with an ostomy.