

Volume XLVII Issue No. 2

Summer Quarter 2017



Broward Beacon



Meetings: June 4th, Summer Break,
Sept. 3rd ~ 1 p.m.

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

BOA is dedicated to keeping you informed on the “how to’s” of self-care; ostomy related products, updates and product reviews; relevant medical research; and educational and social events going on in the ostomy world. Our goal is to help all our members and friends get back to their “previous normal” after undergoing surgery. This journey can be greatly facilitated by sharing it with your fellow ostomates and not attempting to go it alone.



With that in mind, here are some updates! Our own wonderful Medical Board Member, Lea Crestodina hosted Memorial Regional Hospital’s “April Showers Bring May Flowers: Taking Care of Patients with Ostomies & Fistulas” on April 27th from 8:30 a.m. – 4:30 p.m. and featured our beloved Mary Lou Boyer as one of the many guest speakers. Lea was kind enough to invite me to attend as a representative of BOA and I was able to distribute our organization’s contact information to all those in attendance, many of whom had no idea that our support group even exists.

I was given the opportunity to share from the podium that it would be helpful for healthcare professionals to start using liquid deodorant in



pouches immediately after surgery so that the new ostomate will know right away that odor control will not be an issue. The suggestion was well received.

Among other topics, Mary Lou gave an outstanding lecture on *Living with a Stoma; Basic Ostomy Care*. It was such a treat to catch up with Mary Lou since she left us upon retiring from Cleveland Clinic Weston to move to central Florida to be nearer to family.

BOA will take a summer break in July and August starting up again the first Sunday in September.

In August starting on the 23rd, please if you possibly can join Ren and me, Bob our first time visitor’s co-chair, Debbie our Recording Secretary, Krysta our Corresponding Secretary, Darryel our Refreshments Co-Chair, Amparo, and Jennifer as we travel to Irving CA for UOAA’s biennial conference.

I’ve had the pleasure of attending these conferences for the past forty years and I never cease to be encouraged, delighted and well informed by attending. I’ll be teaching a short seminar on Graphic Design for Ostomy Chapter Newsletters.

My wonderful sister Pam will be the Conferences’ opening motivational speaker as she shares her adventures over seven years while circumnavigating the earth aboard the 39 foot sloop her husband Andy built in their Ft Lauderdale back yard canal.



As an ostomate Pam traveled with my 4 year old nephew and 8 year old niece, homeschooling them along the way. She is the embodiment of the adage, “An ostomate’s limitations are most often only those that are self-imposed.”

Just having returned this week from Annapolis MD, Pam speaks all over the country at Boat Shows to standing room only crowds (including Naval Academy Cadets) and I’m so very proud. Details for the conference can be found on UOAA’s website www.ostomy.org

Fondly,
Wendy

Next Meetings:

Sunday June 4th, 2017

Summer Break

Sunday Sept. 3rd ~ 1:00 pm

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

Speakers: 1:30

June 4th



“Sometimes I laugh so hard I cry, and sometimes I cry so hard I laugh,” says our June guest speaker and humor therapist Lotsy Dotsy who will share

her joy as a full-time employee of the Memorial Health Care System for the past 25 years!

Most of Linda Herbert's 8 to 10 hour days are spent at Joe Di Maggio's Children's Hospital helping to distract little patients from their pain by bringing laughter to their world. Originally a respiratory therapist for 10 years, Lotsy has been a professional clown therapist since taking the courses at Broward Community College which changed her life 35 years ago. At first she entertained at birthday parties.

Israel through Hadassah as well as other countries



support or require humor therapy in their hospitals, In South America clowns are required. Lotsy is sometimes referred to adult patients as well.

A hospital volunteer since age 14 as a “Pinky,” she is writing a book of stories told from the children's point of view. Lotsy lives and serves by the 5 C's: Care, Compassion, Communication, Commitment, and Courage and knows without a doubt after thirty-five years that laughter is the best medicine.

Summer Break July & August

Sept 3rd

Many of your fellow BOA members attending UOAA's National Conference August 22nd – 26th will be sharing some of their insights from the great speakers, workshops, Exhibitor's Hall, and yes, even from the parties they will have attended in Irvine, CA. If you personally are unable to attend, this will be a wonderful opportunity to glean some of the information that was shared and get a real feel for what goes on at our National Conferences thus hopefully motivating you to attend yourselves just as soon as possible.

Meeting Dates

Please, if you are as forgetful as I am, take a moment to mark your calendars for our upcoming meetings. This is especially important since the *Broward Beacon* is now published on a quarterly basis. We really don't want to miss seeing you.

Our 2017 meetings will all be held on the first Sunday of the month September through June, specifically June 4th, summer break in July and August starting up again September 3rd, October 1st, November 5th and then our Holiday Banquet by reservation only on December 3rd!

**Minutes General Meeting
March 5th, 2017**

The meeting was called to order at 1:30 p.m. at Memorial Regional Hospital's Main Auditorium



Ostomy, Inc.

Julie Ebel Gareau, President

Judith Ebel Considine, RNET, Founder, 1990

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OSTOMY AND UROLOGICAL SUPPLIES
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by Wendy Lueder, President. The Ostomate's Prayer was read by Leroy. First time visitors were welcomed: Carmen, Aviva, Samuel with his father, Christopher, and Prubencio with his wife.

Other announcements:

1) On the 11th page of the most recent Broward Beacon is a form to fill out to request being placed on the mailing list either by e-mail or "snail mail."

2) The nominal annual dues of \$10 are due now. Please see our treasurer Ren.

3) There are scholarships available for first time attendees to the UOAA's National Conference in California this summer. Please contact Wendy or Amy for further information. Wendy's sister will be the opening speaker this year describing her experience of sailing around the world after ostomy surgery. Wendy reminded us that our restrictions are usually self-imposed.

Amy introduced today's speaker, John Chickey, from Hollister's ostomy product line. John has worked with Hollister for ten years, receiving a well-deserved award at their annual meeting last week. John referenced an article published in the Journal of Wound, Ostomy, Continence Nurses' Society. This article compared ostomates with peristomal skin complications quality of life scores with the general public. In this model, 0 equates to the worst possible health status and 1 equates to optimal health and well-being. People without ostomies had a score of 0.74 while those ostomates with good peristomal skin had a score of 0.75. Those with severe peristomal skin complications scored 0.589 which compared to scores for people with severe heart failure at 0.56. This article also addressed the high cost of dealing with peristomal skin complications due to decreased wear time and increased use of other components to ensure proper fit and adhesion.

CeraPlus is the only ceramide infused barrier product in the U.S. There are at least fifteen published case studies re: the effectiveness of CeraPlus fit and formulation to prevent leakage and thereby protecting peristomal skin. Ceramide is a natural component of human skin. It forms a waterproof protective barrier by linking cells of the epidermis together. CeraPlus barriers are meant to



be used alone without underlying powders or barrier films to allow for the ceramide to actually take care of the outer layer of the skin. Ceramide works WITH the skin to provide for better adherence and skin health by helping the skin to retain its own moisture. John showed products with CeraPlus barriers including one with a "floating flange" for increased comfort and ease when applying pouches on a tender abdomen, soft convexity wafers for better fit in difficult to pouch areas, and a one piece soft convex pouch with a peek-a-boo window to better visual placement when applying but not after the pouch is in place. The soft convex peek-a-boo pouch is a go-to pouch for many inpatient facilities as it accommodates most any stoma. One piece soft convex urostomy wafers will be available soon. Both cut-to-fit and pre-sized wafers are available.

Some of the accessories with CeraPlus includes:

- 1) Barrier rings in 2 inch regular and slim versions
- 2) Adapt barrier extenders which are good to use during exercise including swimming
- 3) Oval and circular convex rings
- 4) Medical Adhesive Remover Spray which does not leave behind an oily residue

John reminded us that we are all in this together to help each other. Hollister has spent the last 95 years on focusing on improving ostomy products and meeting the needs of ostomates to maintain high quality of life. The meeting concluded at 2:30 pm and was followed by the annual Board Meeting.

Minutes General Meeting April 2, 2017

The meeting was called to order at 1:30 p.m. by Wendy Lueder, President, at Memorial Regional

Hospital's Main Auditorium. The Ostomate's Prayer was read by Larry. A big thank you was given to Leroy for providing sandwiches for lunch. New visitors were greeted: Mary Ann, Sophia who is an RN at Memorial who was interested in the attending a meeting.

Anyone with private questions regarding their own care or symptoms, may approach one of the Ostomy Nurses after the meeting. There are six wonderful ostomy nurses in attendance today. Debbie Walde, Eula Fahie-Romero, Glicerio Moura-Tebbe, Susan Magri, Lea Crestidina and Patricia Paxton-Alan.



Broward Ostomy Association is one of over 300 chapters across the nation. The national conference will be held in California starting August 23rd. Wendy's sister is the opening keynote speaker and Wendy will also be presenting regarding how to edit newsletters.

Lynn Wolfson is again promoting the Triathlon for Ostomates which would have been held on Sunday September 3rd. Unfortunately we were just informed that this event has been canceled due to national organizational issues.

Our speaker today is Dr. Juan Nogueras from the Department of Colorectal Surgery at Cleveland Clinic where he has practiced since 1991. Many ostomates consider him not only a great surgeon but also a good friend who focuses on good clinical outcomes and patient satisfaction exhibited not only by his competence but also his bedside manner. Wendy reminded us that the "quality of life is only as good as our surgeon frees us to be with a functional stoma". Dr. Nogueras stated that he has been coming to the BOA many years and enjoys witnessing the

growth and vibrancy of the participants.

Questions Dr. Nogueras answered were the following:

1) Where is the stoma placed? A colostomy is either in the ascending, descending, or transverse colon. A loop or end ileostomy is placed in the small bowel. The loop is often a temporary stoma but can be permanent. A urostomy is created with the ureters from the kidneys being placed into the small intestine and brought out onto the skin surface. This can be a standard stoma requiring pouching or a continent stoma which requires self-catheterizing the stoma. Whichever type of stoma is performed, it is important that there is a good blood supply. The location and protrusion of the stoma is affected by the thickness of the abdominal wall and where in the intestine the pathology lies, but the surgeon makes every effort to place this within the abdominal rectus sheath within visibility of the ostomate, and as a budded stoma.

2) What is a good stoma? It is one that looks like a rosebud with good projection, good peristomal skin, good blood supply, and an adequate lumen without strictures or narrowing to prevent blockages.

3) What can go wrong and why? Peristomal skin irritation is often a problem. As the stoma changes in size, the pouching system needs to be measured to ensure a snug fit. Sometimes a hernia appears which is other parts of the intestine working their way under the skin. A prolapse is when the stoma protrudes ("telescopes") out. Both a hernia and prolapse may require surgical intervention depending upon the extent. If a stenosis occurs, this means there is a narrowing of the inner lumen of the stoma which leads to pain. This may require surgical revision as continual dilation of the lumen can lead to pain and may not resolve the problem.

Preoperative education and stoma site marking or key. The ostomy nurse and surgeon want to avoid creases in the abdomen and scars as well as abdominal folds. As noted, the stoma is best when within the sight of the ostomate. Personal preferences and occupational demands may also help to determine the location of the stoma. There needs to be 5-7 centimeters of flat peristomal skin for pouching purposes. The stoma needs to be above

or below the beltline to prevent trauma to the stoma. Preoperative education and counseling are first steps. This should include activity, exercise, and sex. With many unavoidable exceptions, ostomate's limitations are what they place on themselves.

Thus there are minimal restrictions for an ostomate. Complications do occur at times and a team approach including the surgeon, nutritionist, and an ostomy nurse is critical. You are your own best advocate – do not settle for a potentially correctable stoma related complication. Dr. Noguera challenged the attendees to embrace their new anatomy and to not let their stomas prevent their living a full life.

Questions from the audience included:

1) Do I still need colonoscopy surveillance if the reason for my surgery was due to cancer? Yes.

2) Who do I see first if I have a stoma complication? The enterostomal therapist RN. S/he will then contact the surgeon if needed. Make sure you get a copy of your medical records when you go to see the surgeon. The surgeon works with the mechanics of the stoma. A gastroenterologist works with the function of the stoma.

3) What is a CT enterography? It evaluates blockages for the surgeon to identify location and quality of obstructions.

4) Why do I now get food bolus obstructions? The intestine after surgery is no longer freed up. It is tethered internally at different locations within the abdomen. This may require some dietary modifications.

5) I want to go back to doing martial arts. How can I protect my stoma? This question is probably answered best by CWOC nurses. I, Debbie, looked this up on line. There are actually a few online stores that sell stoma protectors that vary in price from around \$50 to over \$100. Just Google Stoma Gear, Stoma Dome (this was founded by an ostomate), Ostomy Armour, Ostomy Resolutions, and Stomplex. A lot of the sites carry similar appearing protectors and some devices do more than just protect the stoma.

6) I lost two J-pouches due to twisting. This started 1-2 weeks after I returned to the gym. Is this common? There is actually a website support group/forum for J-Pouch recipients. It seems as though

there are many people who lose their J-pouches and decide to stick with a permanent ileostomy due to the complications. At one point, it was mentioned that dehydration from working out could lead to pouch failure.

7) How do I know when I get dehydrated? The symptoms are fatigue, nausea, loss of appetite, and tenting of the skin (when you pinch the skin on the back of your hand and it has a slow return to normal). The best gauge is the color and quantity of urine output. It should not be dark. An easy way to determine how much water to drink is to divide your weight in pounds by 2. This is the number of ounces of water you should drink daily. For example, if you weigh 150 pounds, you should drink 75 ounces of water daily which is slightly more than 9 8-ounce glasses.

8) Why does my ileostomy output change when I have no change in my diet? Intestinal transit is not a constant. Bacterial overgrowth can lead to increased output. Additives in food also can lead to increased output.

The meeting adjourned at 2:30 pm

Respectfully submitted,



Debbie Walde CWOCN
Recording Secretary

Minutes General Meeting May 7th, 2017

Editor's Note: As Debbie Walde was out of town for a family reunion we would like to sincerely and deeply thank Linda Roberts for volunteering as our Acting Recording Secretary this May.

We came in and sat down to a wealth of information. Wendy had several pamphlets laid out for us to browse through while we enjoyed one another's company. One of them was the UOAA's 6th National Conference being held on August 23, 2017 in Irvine, California. Remember this wonderful event only comes once every two years so if you are able, do try to attend. You will be wowed by all the information,

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socials, fun and the friendships you develop with other ostomates while you are there. Registration is \$125 for the ostomate and \$75 per person thereafter. Our discounted rate for rooms at the Hotel Irvine will be \$129.00 a night single/double plus tax and fees ~ but you must register by the deadline date of July 31, 2017.

Thelma and her family stopped by to say hello and share some supplies. Thank you Thelma. Our sincere condolences for the loss of your beloved Joe.

Ever helpful Ren, the love of Wendy's life, was there to say the Ostomates Prayer for our beginning blessing. Once again Wendy thanked our wonderful ostomy nurses who come to our meetings just to help any and all of us. Such giving from the heart is so wonderful to see and is really appreciated. Today we enjoyed the company of our newcomers Heidi with a colostomy and Michael with a urostomy. The help everyone gives our newcomers is unsurpassed.

David A. Gross, M.D. was our honored speaker today. He is a Board Certified Psychiatrist with a private practice in Delray Beach, Fl. Dr. Gross devoted his career to fighting mental health stigma with public education and his research helped with his approach to bio-psychosocial components of Trauma Stress Disorder. His *Conversations on Coping* presentation was in the form of questions and answers. Dr. Gross feels a person needs to understand and accept with the right tools to cope.

In today's dialogue we defined the difference between **Sickness** - a biological disorder defined already and **Illness** - experience of sickness, how the brain reacts to sickness. The person with the cup 1/2 empty attitude doesn't do as well. Don't be a victim, be able to move forward. Today's questions were:

Q. I have an ileostomy for 29 years and was proud of how well I coped for the first 15 years. Now it seems harder and more stressful.

A. It is normal as we get older and slow down. We feel differently. If the ostomy hasn't changed look to psychiatric problems. It is good news if it hasn't intensified physiologically. Then therapy may be needed.

Q. How do you break the cycle of panic/anxiety attacks and the fear that they will return?

A. Panic/Anxiety is false alarms in the brain. It is a medical condition that may require Cognitive Behavioral Therapy and education. No one has died from or had a heart attack from this. You need to learn how to reframe your thinking.

Q. New panic/anxiety attacks came on after chemotherapy. Will they go away?

A. Attacks can be triggered by something and are treatable. Cognitive Behavioral Therapy is the treatment of choice with techniques to train your brain to stop the attacks. Serotonin type medications may help.

Q. What are some techniques?

A. There are medical manuals for relaxation, breathing, and reframing your thinking. Keep logs of episodes to learn how to control them. It takes time.

Q. How do we know which manuals to purchase?

A. The most effective manuals are for the therapist. Authors Barlow and Heinburg have self-help manuals to be used with a therapist and guide.

Q. What is the difference between a panic attack and an anxiety attack? What do they look like?

A. There are two components: Physical - increased heart rate, shortness of breath (this is the most common) and psychological - worrying what may happen ex: what if—. Anxiety is not as intense - you don't fear you will die. Panic is intense and you do think you will die from the attack.

Q. Can you have one without the other? A. Yes.

Q. How do you know if you need psychiatrist vs. a psychologist?

A. Broadly speaking in life situations therapy is helpful from a Mental Health Therapist, Psychiatrist. They can prescribe medications. If you can't bounce back it becomes a biological state and you may need more meds and/or more therapy. Sleep is important. Learn by apps on your phone, counting sheep, Cognitive Behavioral Therapy. Don't suddenly stop meds because you may have a rebound

effect and sleeplessness may return.

Q. Anything else that can be tried?

A. Yoga, breathing from the diaphragm techniques. Learn how to clear your head with meditation Q-reflex (quieting) calms you. You can find UTube videos to look at.

Q. What do you think of marijuana use for this?

A. There are several components of marijuana. Hopefully someday one will be found to help. At present, marijuana is not recommended.

Q. I am a 30 year mental health individual and one month ostomate. The initial diagnosis was quite confusing. I use yoga and library support groups.

A. For most surgeries we aren't prepared adequately. Preparation is critical.

Q. Is there a best time of day to use tapes, yoga etc.?

A. Practice 2-3 times a day to treat for prevention.

Q. Is some memory loss related to surgery?

A. Surgery may effect you for some time but it may also be from stress.

Wendy thanked Dr. Gross and presented him with her delicious homemade brownies, and a plaque. Thank you Dr. Gross for an enlightening afternoon.

Amy gave an update on Jillian. She was recently on Channel 7 News with her dog training for Post-op and Chronic Crohns patients who are not able to bend or lift. She is working on teaching dogs to help autistic and epileptic patients with seizures. The newest training will help people who purposefully hurt themselves. The dog creates a distraction. What wonderful work. Thank you Jillian.

Respectfully submitted,

Linda Roberts

Linda Roberts,
Acting Recording Secretary



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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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).

Belts vs Tape

via Vancouver (BC) Ostomy HighLife

It's sometimes necessary to use extra measures to make sure that an appliance stays firmly in place. Many factors can dictate a need for further measures to ensure a worry-free fit—body shape, skin type, sports played, job demands or quantity of waste. Tape and/or ostomy belts are sometimes a solution. Each has its advantages depending on the individual. In some instances, a combination of both may be recommended.

Ostomy belts are a frequent first choice because they are reusable, washable, adjustable, and don't have to be peeled off the skin. But a belt that is too tight can cause its own problems. Wearing the belt too tight will cause the elastic to become overextended which allows the elastic to curl, forming a rope-like fit instead of a flat fit around the waist. This could get mighty uncomfortable in a hurry. You want the belt to be snug, but not so snug it's digging into you. You also want to keep the belt from 'riding up,' which will create an off-center pull on the appliance.

Try to keep the belt level with your flange. Wider ostomy belts might be more comfortable if one has rolls of fat around the midsection. Most belts are about an inch wide but wider types are available. You might want to allow your pouch to fill up and then test how effective an ostomy belt might be under different tensions and body movements. Choose cloth rather than rubber or elasticized fiber. Cloth will be cooler.

Always empty a full pouch as soon as possible, or better yet, don't let it get that full in the first place.

Some times belts are just not practical. They may be too uncomfortable for the wearer, or spoil the look of some clothes. Tape can be a good solution in such cases.

Tapes come in a variety of materials, paper porous tape, all plastic tape or a combination of both. Some appliances come with a tape perimeter 'built-in' but you may still need to apply another layer over the top of this. Tape is relatively inexpensive so give different materials and brands a try. To properly apply tape, it should encircle the entire flange, with one half on the flange and the other half on the skin. In time you'll get skilled at applying this. A gentle pressing-

on with the finger tips will ensure that it's stuck.

Most problems with tape arise from poor application technique, impatient removal or allergies to the material. Prepare the skin with careful removal of the old flange and thorough cleaning and drying of the skin. When removing the tape, use the 'two hand' method—one to gently pull the tape off and the other to hold the skin down. Too frequent or rushed tape removal can cause irritation.

Either method or even both methods—tape or belt—can greatly increase your confidence and comfort. Give both a try if you have concerns about your appliance staying in place.

Memorial Outpatient Ostomy Clinic

To make an appointment call 954-265-4512.

South Florida Ostomy Support Group

At Baptist Hospital. For more information, call Lourdes Placeres at 786-596-6036.

Coral Springs Support Group

For more information, contact Patricia Paxton-Alan MSN, ARNP-BC, CWOCN at 954-344-3094.

We Get Mail



Dear Broward Ostomy Association,

I want to thank you for the VERY generous gift card to AC Moore. I truly appreciate all of your support during these past few months where I have had six surgeries and three hospitalizations. The phone calls and texts give me the strength to conquer my physical challenges.

I will use the gift card to purchase yarn to make hats for cancer patients and any other patients who are need of a hat. I find the knitting distracts me from my pain. Through creating a hat, I am turning negative energy into positive energy and making someone else very happy. That makes me feel so good! Thanks so much again!

Fondly,
Lynn Wolfson