

Volume XLVIII Issue No. 3

Fall Quarter 2018



Broward Beacon



Meetings: September 2nd, October 7th
November 4th ~ 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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Meeting the Challenge

by Harold W. Spaet, President MOA

Edited by Mary Lou Boyer, BS Ed, RN, WOC Nurse

MOA Educational Coordinator

Wendy's Editorial Note: *The following is an introductory website message from Hal, the founder of Miami-Dade's new support group, **Miami Ostomy Aftercare**. Please do take the time to visit this fine and extremely informative site, www.MiamiOstomyAftercare.org. Hal says it all. Mary Lou, the editor, is a long time friend of BOA and served many years at Cleveland Clinic Weston, earning a **Lifetime Achievement Award**. Congratulations Hal. Difficult job, well done.*



When you first have ostomy surgery, it can feel as though your world has turned upside down. There is so much to learn and so many emotions running through your mind. You may feel as though you will never figure out how to do the things you need to do and

that you may never lead a normal life again.

Hospital stays are short and it is so difficult to grasp all of the hospital instructions while your mind is still hazy from anesthesia and medication. What teaching has been done is hard to remember when you are suddenly on your own.

You are not alone in your thoughts and feelings!

This not-for-profit organization was formed from just such a need, by a patient who found himself coming home from the hospital after urostomy surgery, unsure of what to do as pouching problems occurred.

After much searching, and many leaking pouches, he found scattered information here and there and eventually got the help he needed. This website is intended to provide accurate information and education in various forms, as well as resources to ease your adaptation to your new way of life.

Ostomy care teaching is best with a trained os-

tomy nurse; however there are not enough of them, nor enough hospitals and home care agencies with specialized ostomy training. These are few and far between. It can be very hard to find the help you need, so we created this site to aid both patients and caregivers, including medical professionals.

We have attempted to provide a very comprehensive website with video demonstrations of pouch change procedures and other care needs, written information and instructions, as well as a telephone Help Line where you may call to ask questions. We will continue to add new information and make this site as inclusive and up-to-date as possible, so you will have everything you need at your fingertips

We are even going a step further. The Miami Ostomy Aftercare Program has contracted with the Wound Ostomy and Continence Nurses Society to provide education and hands-on training for nursing professionals to improve skills in ostomy care. It is our hope that they will, in turn, fill the need for more hospitals and home care agencies to have staff that can truly provide ostomy care education for patients.

In addition, you will find information about our ostomy support group, affiliated with the **United Ostomy Associations of America**. Groups such as this help you to meet others who are going through similar situations. Informative speakers are a part of each meeting as well as time to ask questions and share with others.

The transition from the surgery and hospital stay, to discharge home, and on to healing requires managing life changing processes that progress to leading an active productive life. This process takes time. The reason for surgery and the procedure may be different, but the result is that things have changed and learning how to care for an ostomy is a priority. Much of it is relies on your attitude and the aftercare that you receive. It can be overwhelming, but Miami Ostomy Aftercare is here to help you.

Use this website to find videos and written information to show you the steps for changing an ostomy pouch, and information that you can use every day as you get used to new methods and habits. There is much to learn and so much to feel. Let us help!

It's all about Aftercare!

Next Meetings:

Sunday Sept. 2nd ~ 1:00 pm

Sunday, October 7th

Sunday, November 4th

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

Speakers: 1:30

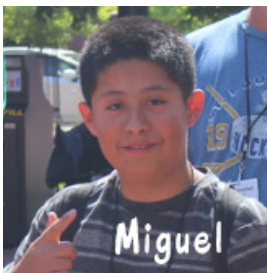


August 28th, 2018 Miami Ostomy Aftercare Support Group's Meeting

"Adjusting To Living Life With An Ostomy", Dr. Mary Ann Meli (Licensed Clinical Psychologist). 6 pm to 7:30 pm—University Of Miami Hospital and Clinics UMH Boardroom #2026 (Lobby

level-2nd floor) 1400 NW 12th Avenue, Miami, FL 33136 Parking garage next to the main entrance. Free of charge with validated ticket. For more information call 786-580-3928 or email moap@miamioostomyaftercare.org. This is **not** a BOA meeting.

BOA's September 2nd Meeting



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.

Miguel, our Youth Rally Camper, will also be joining us to share his camp adventures in Colorado. We thank you for your generosity for helping to send Miguel to this youth ostomy camp.

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.



World Ostomy Day, Oct 6th, 2018

World Ostomy Day is sponsored by the International Ostomy Association (IOA) and is celebrated every three years. This year World Ostomy Day will be held on Saturday, October 6, 2018 and UOAA is excited to join our national efforts with the rest of the world on this special day. This year's theme will be "Speaking Out Changes Lives." The aim of World Ostomy Day is to improve the rehabilitation of ostomates worldwide by bringing to the attention of the general public and the global community the needs and aspirations of ostomates.

BOA will be celebrating this event on Friday, October 5th with a lobby display table from 11 am to 1 pm as a guest of Cleveland Clinic, Weston FL.



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BOA's Oct. 7th Meeting

BOA is thrilled to have as our October guest speaker David J. Maron M.D. who is the Vice Chair of the Department of Colorectal Surgery and Residency Program Director at Cleveland Clinic Florida.

Dr. Maron graduated with a Bachelor's degree in liberal studies from the University of Pittsburgh. He then obtained his medical degree from Georgetown University School of Medicine. He completed his general surgical residency at Thomas Jefferson University Hospitals in Philadelphia. During his surgical residency, he also obtained a Master's in Business Administration from Drexel University. He then completed his residency in colorectal surgery at the Cleveland Clinic Florida. He served as an assistant professor of surgery at the University of Pennsylvania for 5 years before returning to his current position at Cleveland Clinic Florida.

Dr. Maron has an interest in minimally invasive colorectal surgery and sphincter sparing procedures for rectal cancer. He serves on multiple committees in ASCRS and is currently the vice chair of the CME committee. He has numerous publications in peer-reviewed journals, and has authored more than 15 book chapters. Wow!

He will be speaking on the topic of blockages, how to avoid, self-diagnose and then what to do if you think you do have one. He will also hold an any-topic question and answer session for all.



BOA's Nov. 4th Meeting

Oh how I look forward each year to having Mr. Rob Seaman of ConvaTec join us once again. The year's photo is of Rob and his beautiful wife of 38 years, Deborah in

Patagonia, Chile. Since we've seen Rob he's also won 1st place in his age group in a cancer charity run.

As many of you already know there are three major manufacturers of ostomy supplies, ConvaTec, Hollister, and Coloplast as well as specialty product manufacturers such as Torbot, Parthenon, Nu-Hope, Cymed, and Celebration Support Belts, etc.

Every ostomate is unique and what works well for one does not necessarily work well for another. Each of us needs to be aware of the different pouching products available and use what's best for their own particular situation. I personally prefer one manufacturer's barrier wafers yet prefer another manufacturer's pouch. Do learn what options ConvaTec has for you and be an informed, comfortable ostomate. It is only when we can manage well physically with our pouching system that we can happily get on with our lives.

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.

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 May 6th, 2018

The meeting was called to order at 1:30 pm in Memorial Regional Hospital Auditorium in Hollywood, Florida by Wendy Lueder, President. The Ostomate's Prayer was read by Larry. First time visitors were greeted: Jans, Emiliano and daughter, Robin. Leroy and Emma were thanked for providing sandwiches and refreshments.

Announcements: Miami Ostomy Aftercare Support Group is going to have its inaugural meeting May 22, 6-7:00 pm at Jackson Memorial Hospital. University of Miami and Aventura Hospitals have joined forces to provide this much needed service

for the Miami-Dade area. For more information call 786-580-3928. More information can be found online at miamioostomyaftercare.org.

There will be a *Fearless Caregiver Conference* held in west Broward County June 20. This is a very interesting opportunity to attend this conference about, for, and by caregivers. More information can be found online.

Miguel, who is known to BOA as the young man we helped send to Youth Rally last year, has announced that he would love to go again this year. The camp will be held in Boulder, Colorado. Donations will be much appreciated.

Thank you to Melvina for volunteering to be in the main lobby to hand out visitor tags for attendees at BOA. Ask Melvina's husband re: his opinion on using the Stealth Belt – he says he loves it.

Patty Paxton-Alan introduced today's speaker, Dr. MaryAnn Meli. Dr. Meli received her degree from Nova Southeastern University. She specializes in pain management, depression, and adjusting to life after surgery. These are topics with which she is well acquainted because she has been an ostomate herself for the last five years. In her spare time, Dr. Meli breeds champion beagles.

Dr. Meli's father had an ostomy many years ago when there were no support groups and product variety was very limited. Now there are many types of products manufactured by multiple companies to address personal preferences and needs of the ostomate. Support groups are springing up locally, whether as affiliates of the national United Ostomy Associations of America or not. There are now so many resources available for the ostomate. Dr. Meli talked about how she set her alarm clock every two hours during the night to make sure her pouch was emptied to prevent leakage. The possibility of leakage is of concern to everyone. This is one of the many factors of the universality ("we are all in the same boat") of having an ostomy. It was by going to a support group six months after her surgery that she found how to address problems with leakage.

How to Deal with Depression

Many attendees wanted to know how to deal with depression. Dr. Meli suggested reframing your

thought processes. Instead of grieving over the loss of "normal function" or "body image", focus on what you have gained which is freedom from illness or being chained to the restroom. She encouraged us to not become a slave to irrational fears. Nothing that could happen (such as leakage) will be the end of the world. Some accidents happen regardless of surgical interventions such as in the case of ulcerative colitis.

In some cases, pain is also present as much before surgery as after surgery. "It's what we tell ourselves about the event, not the event itself" that affects our moods. What one thinks, feels, and how we act that determines our reaction. This works vice versa as well. Our reaction determines what we think, how we feel, and how we act. We may not be able to change the situation, but we can change our outlook and response to the situation or event.

Dr. Meli discussed rational vs. irrational beliefs. Looking at all the negatives is irrational. This was confirmed by one attendee whose surgery was ten months ago stated she had two family members who passed away because they did not want a stoma. She accepts her ostomy and is grateful to be alive.

Dr. Meli told us that depression is a thinking disorder – it is what we tell ourselves. Crying is a healthy way of releasing emotions. However, if crying pulls you off track and you can't seem to stop, then it is time for self-talk to reverse this downward spiral.

Pain and Anxiety

Q: Not all pain is treatable and some prognoses are unavoidable. How do you deal with it?

A: How you respond is still your choice. You can choose to enjoy your good days. Do research for help and/or hope to find alleviation of the pain. Look at what you are able to do in spite of the pain. Focus away from the pain. Find things to divert your attention. You can accept the pain but don't let it defeat you.

Q: One attendee stated her grandmother lived with pain and how she dealt with it was by using her "mental muscle" to work out each day. Like any muscle, it takes habitual focus and grows little by little.

A: Pain can be an indication that something is

going on. Be sure to go to a specialist if needed.

Anxiety is a natural adaptive function of which you cannot rid yourself. How to deal with it is with breathing exercises to ride out the storm. Anxiety is related to the sympathetic nervous system. The parasympathetic nervous system can help alleviate that anxiety when you breathe deep which forces you to relax. Other methods are eating, yoga, affirmations, and meditation. Walking will also help to decrease the anxiety. There is a grounding technique one of the attendees mentioned which is also found on the internet. It involves sensory and cognitive awareness focusing on the here and now. It involves what is called the 5-4-3-2-1 method.

- Name five things you can see right now.
- Name four things you can feel/touch right now.
- Name three things you can hear right now.
- Name two things you can smell right now.
- Name one thing you can taste right now.

The meeting adjourned at 2:30 pm.

Minutes General Meeting June 3rd, 2018

The meeting was called to order by Wendy Lueder, President, at 1:30 pm June 3, 2018 at Memorial Regional Hospital Auditorium in Hollywood, Florida. The Ostomate's Prayer was read by Larry.

First time visitors welcomed today are: Rhonda who is author and editor of "Optomistically Yours"; Fred who is Jennifer's father and has had an ostomy for thirty years; Louise and guest, and Carol who had her surgery one month ago.

Leah gave an update on Miguel – his application for Youth Rally has been completed and he is excited about attending this summer. Other updates: Melvina was thanked for being the lobby attendant initial greeter. Bob asked re: interest about organizing a cruise for ostomates.

There will be no meetings in July and August for summer break.

The new Miami-Dade Support Group, *Miami Ostomy Aftercare*, held at Jackson Memorial Hospital had 28 attendees for its inaugural meeting in May.

Most Frequently asked Questions of New Ostomates

Today's meeting consisted of CWOC nurses addressing most frequently asked questions by new ostomates. The CWOC nurses introduced themselves as follows:

- Eula works at Memorial West. She has been nursing for 32 years. She does see outpatients as needed. A prescription with a diagnosis is required. She also educates patients prior to ostomy surgery.

Eula's advice to new ostomates is to expect the stoma to shrink. This requires measurements and probable change with pouches. The prescription for pouches will need to be changed if this is the case.

- Lea works at Memorial Regional and Joe DiMaggio's Children's Hospitals since 1991. She had taught WOC nursing at Emory University as well. Leah informed the group that this year the Wound, Ostomy, Continence Society is celebrating it's 50-year anniversary. Lea sees patients on an outpatient basis also with a prescription and authorization by their insurance company.

Lea's post-op patients are often concerned re: getting possible infections related to the stoma which requires reassurance that this is not the case. They are also concerned about how to get supplies when they go home.

- Debbie has been certified for 6 years, a nurse for 39 years. She works at Broward Health Medical Center. There is presently no outpatient clinic set up for ostomates.

Debbie's most frequently asked questions are about showering or bathing.



Those patients are told about *Press'n Seal* available at the grocery in the aluminum foil aisle adheres to the skin and pouch during showers. Pouches are made to adhere to the skin even in water. Some people use a hair dryer on cool setting after the shower to ensure drying of the pouch.

- Patty is an Adult Nurse Practitioner and has been CWOC nurse for more than 30 years. She was formerly employed at Broward Health Coral Springs.

Patty has addressed concerns both pre-op and post-op re: odor. She informed patients that ostomy

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pouches have an odor proof lining along with filters. She has told them to clean stool off the ends of the pouches and to cleanse the wafers when changing pouches when using a 2-piece system.

Conversations ensued:

- It was suggested to wait 4 hours after new pouch application prior to getting in the water for swimming, bathing, or using a hot tub.

- Coloplast barrier strips are often used to provide a longer wear time of the pouching system – they come in 3 different shapes to meet anyone’s needs.



- *DryPro Ostomy Protector* is a water-proof device available online. Your waist size measurements are needed for the pump for the vacuum seal to be effective. It is made of latex. This is a new product (2018) and costs \$55

or more available online.

Darryel and Ed came to visit our meeting from California. Darryel talked about how California is hot leading to increased sweating. Sometimes this leads to a fungal rash which can itch and burn. Over the counter Miconazole 2% to use while crusting can be beneficial in this case.

Lea received a question re: how to prevent or treat blockages of ileostomates. She was told by an ileostomate WOC nursing student to avoid foods that are not fork tender for easiest and best results. Symptoms of a blockage are pain, cramping, and watery output. Warm baths, hot tea, and massaging may be of benefit. Seek medical care if you are unable to relieve blockages on your own. Sometimes a gentle irrigation using a small catheter is needed once any other complications have been ruled out with x-rays. UOAA provides an Information Sheet on Ileostomy Blockages for free. Information is

for both at home treatment and Emergency Room treatment. To download go to:

https://www.ostomy.org/wp-content/uploads/2018/01/IleostomyBlockage_2018.pdf

For sensitive skin it was advised to keep things simple. A **no-sting** barrier, a protective ring, crusting with powder and prep wipe/barrier spray, or using *Hollister’s CeraPlus* wafers.

For loose stools, the best pouching systems are those that have extended wear barriers. There are multiple ideas of how to thicken output, there are many suggestions online including United Ostomy Associations of America.

There are challenges unique to urostomates especially when using one hand. Use precut pouches and change first thing in the morning before drinking anything. Plug the stoma with a tampon while using a 2-piece system.

Peristomal hernias are one of the most common complications. If there are no associated pouching problems, it may not need intervention. Hernia belts, panty girdles, maternity bands, can all be used with effect.

The meeting concluded at 2:30pm with ongoing discussions among the attendees.

Respectfully submitted,

Debbie Walde
Recording Secretary



Mark Your Calendar for UOAA’s National Conference!



Join us August 6–10, 2019 in Philadelphia, PA, for the ostomy communities’ premier educational and social gathering. Top Medical Professionals; Inspirational Stories; Free Stoma Clinic Appointments with WOCNs; Product Exhibit Hall with 25+ Vendors; Social Events

On and Off-site; ASG Leader Networking; Dedicated Sessions for Caregivers and Family; Vacation Destination; and Sexuality. New for 2019! Medical Marijuana and Alternative Pain Management; Clothing Modifications: Pediatrics/Young Adult Track; Ostomy Belts, Wraps and Accessories – (what’s up with all those products). Many *Topics Designed for the Experienced Ostomate. All are Welcome!

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.

Miami Ostomy Aftercare Support Group

As this new Miami-Dade support group meets at various locations, call or email to verify meeting times and location. Call 786-580-3928. Email moap@miamiostomyaftercare.org. Mark your calendar for MOA’s August 28th and September 25th meetings.



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

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(This information is kept in the strictest confidence.)

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