

Next Meeting:

September Sunday, September 4th, 2011: 1 p.m.

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

Broward Ostomy Association

Our Vision Survival Out Vi

An affiliated chapter of the United Ostomy Associations of America. Our Vision ~ a society where people with ostomies are universally accepted and supported socially, economically, medically and psychologically.

www.browardostomy.org 24 Hour Hotline (954) 537-0662

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

Every two years the United Ostomy Associations of America, our mother organization, puts on a fabulous National Conference, this year in Reno NV with 604 attending. Two years ago I had the privilege of being asked to serve on UOAA's National ASG (Associated Support Group) Advisory Board. So this year they were kind enough to pay my airfare, hotel, registration and food expenses. BOA also was kind enough to pay Ren's Registration and Banquet fees so he and I just returned home from having the time of our lives.

UOAA put me to work which I was more than delighted to do. All day Sunday, Aug. 7th, from 9 to 5, I attended a Management Board of Directors Meeting where important goals and strategies for

the upcoming year were determined and clarified. After that I was a co-speaker along with Bob Baumel, UOAA's Webtech, on *Your ASG and Its Website*; a panelist along with David Beck M.D., Mary Malone, CWOCN, and ileostomate Bob Baker on *Basic Ileostomy*; a fashion model (do you believe that!) for Hollister's *Social & Fashion Show*; and a moderator for four of the over 45 different speaker breakout sessions.

The conference was a wonderful balanced mix of academic learning sessions, updates by ostomy product exhibitors and oh so fun social events. Ostomates from all over the country and as far away as the Philippians and Iceland partied like the best of them. I think Ren and I were probably the only ones who didn't gamble, but then again we had no losses.

In this issue I hope to share as much as possible of what I learned. I also hope that some of the joy of the event spills over too as we both returned home totally edified and rejoicing that a group of people who have gone through so much can get together and celebrate life, knowing that it isn't what happens to you that's important, but how you respond throughout the journey.

Fondly with love,

Wender

2011 UOAA National Conference Products Review

Attempting to take in information from the dedicated ostomy vendors in Exhibit Hall was one of the highlights of the conference. I was thrilled to learn that even after all the progress I have witnessed in product development throughout the years, new exciting advances are still being made.

One of the complications ostomates may have is peristomal hernias. I know many of BOA members have been challenged by this issue. Nu-Hope Laboratories (800-899-5017) has made a quality hernia/ostomy support belt for years. However a new belt is on the market that includes three very useful additional features.

The Medicare Approved Celebration Ostomy Support Belt (\$90 through Parthenon Ostomy Supplies 800-453-8898) includes a removable soft plastic hernia plate giving extra tummy support; an optionally worn strong plastic stoma shield



Next Meeting:

Sunday, September 4th, 2011 Refreshments, 1:00 p.m. Chat 'n' Chew till 1:30 p.m. Meeting: 1:30 p.m.



We have a terrific meeting scheduled for you this September where fourteen year old L.T. will be sharing with us his adventures along with 130 other very young ostomates at Youth Rally in San Diego this past July. After speaking with several of L.T.'s counselors that I met in Reno, I know your generosity in sending him to Youth Rally was very well spent as he was fully involved and had the time of his life.

Linda Aukett, one of the founders of UOAA, even said to me that L.T. was so well engaged at the Rally that she would not be surprised if he did not move up into leadership involvement in the coming years.

Also I will be sharing some of the wonderful discoveries Ren and I made while attending UOAA's 3rd National Conference in Reno NV this past August 6th through 12th. I am so very glad I was able to attend and bring back information and samples not only on new, helpful products but also important information I learned at the many workshops and

seminars. It never ceases to amaze me how little I really know after all these years of being an ostomate.

I truly look forward to seeing you all there and want to take this opportunity to sincerely thank Lea Crestodina, one of our Medical Advisory Board members, for all the hard work and extra efforts she took that enabled L.T. to attend the Rally. Without her help L.T. would never have been able to attend.

2011 Meetings Schedule

If you are as forgetful as I am (and it's really getting worse - why did I just walk into this room?) here are the dates of our upcoming meetings so you can put them in your date book now.

September 4th, October 2nd, November 6th and December 4th, our holiday banquet at 4:30 p.m. by reservation only.

New UOAA Veterans Outreach Program

The UOAA has started a program to assist in creating "no membership fee" ostomy support groups serving ostomates in the Veterans Administration Hospitals and Clinics system.

CW4 Robert W. Cuyler is an ostomate and is on active duty in Afghanistan. He will be flying until October and will be carrying a supply of 3' × 5' flags on these missions. To receive one of these flags and a beautiful certificate please consider contributing \$150.00 or more to UOAA with the designation VA Program and send to: UOAA, P.O. Box 512, Northfield MN 55057-0512.

Coral Spring 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. As does BOA, Coral Springs takes a summer break so be sure to call to confirm meeting dates. For more information call Patricia Paxton-Alan MSN, ARNP-BC, CWOCN at 954-344-3094.



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To learn more, call 1-800-422-8811 or visit www.convatec.com/moldable

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Products Review continued from page 3

(stoma cup guard) which protects the stoma from any work-place, sports or seat-belt trauma; and an adjustable pocket which holds the pouch weight as it fills and prevents it from moving during intimate moments. The part of the belt that wraps around the body is a light, airy open-weave elastic. The part of the belt near the stoma is soft, comfortably padded tricot. For more information see: www.Cel-

ebrationOstomySupportBelt.



Another remarkable product is a portable, great-fortravel **Night Pouch System** (702-540-1555) for urostomates. A strong, large hard plastic T is placed between any bed's mattress and box spring. Your own night pouch is placed into a vinyl,

leakproof pouch that securely attaches to the plastic T and is secured with Velcro. It is easily carried to the bathroom as needed. For more information: www. NightPouchSystem.com.



Thanks to the generous support of an educational grant from Coloplast Corporation, the American College of Surgeons Foundation has a brand new **Surgical Patient Education Ostomy Skill Kit** for ostomates, their family members and/or caregivers

to learn the fundamentals. The boxed kit includes a professional quality DVD demonstrating important self-care techniques as well as the why and how of surgery, a workbook, and a life-size faux stoma with real sample pouches to help you practice appliance application. Ideally the kit would be given to an ostomate before surgery but I would recommend the kit to anyone new to this surgery.



The Foundation became aware that "up to 80% of patients do not receive the desired amount of information at discharge, resulting in a lack of confidence and knowledge on how to properly manage their home care."

The kits can be ordered through www.SurgicalPatientEducation.org or 312-202-5263. Cost \$40 plus shipping.

One of the misconceptions I have harboured for years is that using adhesive remover is unnecessary. That is because I only needed to change my appliance about once a week. Now with my retracted stoma it's about every other day if I'm lucky. With frequent changing an adhesive remover is essential as your skin can be traumatized by the procedure.

Up until now Smith-Nephew's Uni-Solve Adhesive Remover was the only one I was aware of. It comes in small wipes and leaves a sticky difficult residue. Now the good news. There are two new adhesive remover sprays that leave no residue and are oh so easy to apply. Just hold down the nozzle of the spray can and aim at the edge of your skin barrier wafer.. Wait a few seconds and off it comes. Additional spray applications are needed as the barrier peels off.



The nozzle on Trio-Niltac Sting Free Medical Adhesive RemoverTM is more comfortable to aim than the Coloplast Adhesive Remover Spray and appears to need less product for the same effect. Trio was kind enough to send me samples that will be distributed at our September meeting. Contact Trio Niltac toll free at 855-

289-8746 or Coloplast at 800-788-0293.

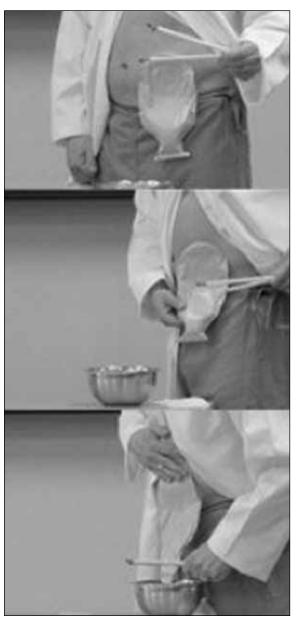
Trio Healthcare just entered the US market from England and has two additional products of interest. Silesse™ Sting Free Skin Barrier is a silicone protectant that moisturizes and soothes, does not sting, even on sore skin and dries quickly – allowing you to apply the next adhesives in seconds. I have tried samples twice and like the product. It doesn't build up in 'layers' and is hypo-allergenic. It comes as a spray or wipe but I like the wipe as I have more control over where it is applied. My barrier removal was far more gentle on my skin when I used Silesse.

Trio Diamonds™ Gelling & Odor Control Sachet combats pouch ballooning and odor for ostomates that have a watery output. A very small packet dropped into your pouch after emptying becomes a semi-gel when it come into contact with output which in turn helps with leakage control and less frequent emptying. As far as I am aware, it is the only gelling product such as Ile-Sorb, Ostogel, or Gel-X that has odor control as well as the gelling effect. Prices vary widely.





One Pass Ostomy Draining Device is a great gadget but only if you have severe hand arthritis or a caregiver that has difficulty helping you empty your pouch. Personally I think every hospital's surgical floor should have one. Only drawback, very, very, expensive. It is a hand-held device with two rollers that squeezes the contents of your pouch completely out with one pass. Contact www.opodd.com



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Memorial Hospital West is dedicated to addressing the unexpected and changing needs of people who are preparing for or living with an ostomy. We can help with ostomy care, including:

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Product Review continued from page 7

Hollister has a great improvement on their "Lock 'n Roll" Microseal Drainable Pouch Closures. The previous version had a more Velcro-like composition where output could be trapped and not easily be cleaned off. The new Velcro-like material is much flatter and could be easily cleaned if output accidentally comes in contact. The closure is also curved and designed to rest comfortably against our bodies. Well done.

Hollister has a brand new flat skin barrier that is similar to ConvaTec's moldable wafers. FormaFlex Shape-to-Fit extended-wear skin barrier is simple to shape and reshape by hand for a customized fit around various stoma sizes and shapes. No measuring, no tracing and no cutting is needed. Unlike ConvaTec's moldable wafer which you need to roll and pinch into shape, the FormaFlex is pushed sideways into shape with no overlapping of the material. It does not come in a convex wafer at this time.

OstoMySecrets has a line of underwear, comfort wraps and swim wraps that support and conceal your ostomy system with a built-in pocket to hold your pouch. I purchased a Vixen Wrap for intimate times that has black ruffles on the front with pink in the back. The ruffles give complete discretion holding the pouch in place and made me feel very feminine. Ren could care less but it made me feel good about myself. Contact at 877-613-6246. The adorable blond Cricket on page 5 works for the company.



Another ostomy pouch wrap gets my Editor's Choice Best New Product award, Undercover Designs MY DIGNITYTM.

Unlike other products that are made using heat and moisture trapping synthetic materials, this wrap is made with soft, natural germ fighting Tencel® fabric

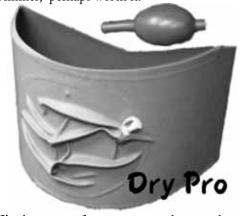
made from the wood pulp of eucalyptus trees and 6% spandex which stretches four ways. It is very soft and comfortable and chemical free. It is worn "around the midriff and upper abdomen ...gliding over pouch lines so your privacy is maintained." What I like about it most is that the natural fabric draws away

moisture and locks it into the fiber. Your skin remains dry. It closes with flat Velcro strips. It's made in the USA and is very reasonably priced. Call 919-601-2993.

Another product that's been on the market 17 years but is new to me is the Waterproof Ostomy Protector by DryPro. The company is sending bro-



chures and a sample so I'll be giving a review of it as soon as possible. It uses a vacuum seal created by a removable hand pump that appears to make it very effective. It is made from surgical latex and can be used daily. The gas filters on ConvaTec's pouches are ruined by water so I really hope this product works. The company also makes waterproof PICC, cast, prosthetic and bandage protectors. Contact Dry Pro at 888-337-9776. A bit expensive but if you're a swimmer, perhaps worth it.



I've be aware of some cute pouch covers but at this convention I was overwhelmed by the attractiveness of a company product of which I was previously unaware. I wish this issue were printed in color so you could delight in just how great these covers are. I'll show some color slides September 4th so those of you who can attend can see for yourselves.

My Coveralls (call 304-724-7286 or on the web see www.mycoveralls.com) are custom made by

Product Review continued from page 9

artisans using designer fabrics, decorative accents and specialty sewing techniques. The skin side is made with comfortable material that wicks away moisture and keeps your skin feeling cool and dry. The bottoms are fitted with Velcro for easy opening and closing. They custom fit your cover so it works with any system you're using. Amazingly, they are truly elegant! Look at this.



Pink satin with embroidered flowers and crystal embellishments

I just spoke by phone to Cindy Sylvia, the owner of MyCoveralls whom I met in Reno in the Exhibitor's Hall. Knowing the value of seeing her products in full color she was gracious enough to offer to mail us full color brochures which I'll be happy to pass out September 4th. Cindy is a CWOCN (ostomy nurse) with over 25 years of clinical experience and also an ostomate since 1977. She asked a professional seamstress to help her design covers that would make her feel pretty. It worked and now she's sharing the joy with all the rest of us.

There is a new web based resource designed to help ostomates, their families and healthcare professionals learn more about **Short Bowel Syndrome** (SBS). Nine important subtopics are covered as well as tips from people with SBS on topics such as eating out, who represent you in Washington.

staying active and traveling. You can confidentially register online at ShortBowelSupport.com. Sponsored by NPS Pharmaceuticals.

In next month's issue I'll compile a list of important observations that the various speakers shared with us. Again, thank you for letting me represent BOA at his special event. It was an honor.

Important Advocacy Issue

We all familiar with the phrase, "Houston, we have a problem". Unfortunately we as ostomates need to contact our Congressmen and Senators for help. At present ostomy supplies are miscategorized a "durable medical goods". They need to be correctly categorized as "prosthetic supplies" to ensure that the government understands their essential need by all ostomates. H. Res. 152 and S. Res. 95 recognize: (1) the lifesaving role of ostomy care and prosthetics in the daily lives of hundreds of thousands of people in the United States,

- (2) the necessity of a specialized ostomy nurse to recommend and customize ostomy prostheses, and
- (3) that a patient undergoing a surgical procedure that results in the patient needing a prosthetic that manages or restores intestinal or urinary system function should have access to individually prescribed, customized prosthetics that will best meet the patient's needs.

Urges: (1) that ostomy products be recognized, categorized, covered, and adequately reimbursed by Medicare in a new payment category of "prosthetic supplies"; and (2) the Secretary of Health and Human Services (HHS) to ensure that HHS programs, policies, and payment practices facilitate innovation of and access to medical devices that restore or improve intestinal or urinary system function of individuals with an ostomy.

You may have noticed that such issues have never previously appeared in the *Broward Beacon* as BOA never has been nor ever will be a political advocate. However our statesmen need to know the truth and protect our very real needs. With budget cuts right around the corner please consider what you might do to address this important issue by contacting those who represent you in Washington.

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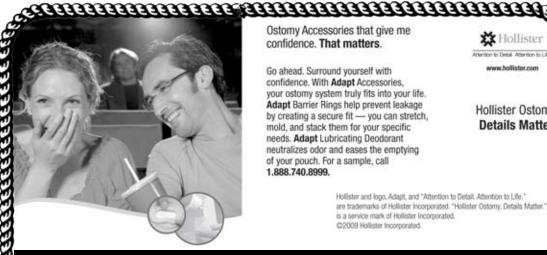
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Broward Ostomy Association Membership

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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CityZip		Phone						
E-mail address 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.)								

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