

Volume XL Issue No. 7

September 2010



Broward Beacon



Next Meeting:
Sunday, October 3rd, 2010: 1 p.m.

Broward Ostomy Association



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

You might remember me mentioning that this spring Ren will be celebrating a big birthday with a fat zero on the end. We're tentatively hoping to go on a cruise but are keeping the dates open as we want to go when our extended family can join us. Having fun with loved ones is **always** twice the fun.

Well, fellow ostomates, we're family too so it's not too early to ask you to join Ren and me, Amy and others at UOAA's National convention next August. Please if you possibly can, be there with us. It is life-changing to be with 100's of ostomates from all over the continent sharing, learning and just having fun. Hoping to see you there.

Wendy



SEE YOU IN RENO NEXT AUGUST

Websites for Ostomates

via Ostomy Network

This is a short list of some of the most popular and resourceful ostomy-related websites. All of them have unique features and content, but are united in their common goal of providing support and useful information to people with ostomies.

MeetAnOstoMate.com is an online community for people with ostomies. If you want to find a friend, need someone to talk to, or consider a relationship - this is a great place to start. You can use the site to find other people with ostomy in your area and also around the world; make friends and maybe even more; get answers to your questions from Ostomy nurses or other ostomates; use the Forum, Chat, Instant Messenger, or your personal Blog; create your own profile; upload photos; watch ostomy-related videos; publish ads.

C3Life.com is a website dedicated to helping people with ostomies live their lives to the fullest. Supported by Hollister Incorporated, the C3Life.com initiative is an outgrowth of Hollister's mission as an organization to help make life more rewarding and dignified for those who use its products.

UOAA.org United Ostomy Associations of America is an association of Affiliated Support Groups. UOAA serves people with ostomies and

other intestinal & urinary diversions through its support groups, by providing information, by coordinating Advocacy efforts and holding conferences, and with services provided via this website, such as their Discussion Board, which has a thriving user community, and a variety of tools to help our affiliates be as effective as possible. Individuals can join UOAA by joining one of its Affiliated Groups. UOAA is a member of the International Ostomy Association.

Ostomates.org The aim of this site is to try and give you as much information as possible regarding ileostomy, J pouch, colostomy, urostomy or any type of stoma surgery. You may have already had surgery or are contemplating it because you have Ulcerative Colitis or Crohn's Disease or some other cause for surgery. It is for ostomates by ostomates (no "medical speak") so remember, these pages are for you.

<http://wocn.org/> Wound, Ostomy and Continence Nurses Society (WOCN) is a professional, international nursing society of more than 4,600 healthcare professionals who are experts in the care of patients with wound, ostomy and incontinence. The WOCN supports its members by promoting educational, clinical and research opportunities to advance the practice and guide the delivery of expert health care to individuals with wounds, ostomies and incontinence. To find even more helpful links see: **<http://browardostomy.org/links.html>**

Next Meeting:

Sunday, Oct. 3rd, 2010

Refreshments, 1:00 p.m.

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

Meeting: 1:30 p.m.

Have you ever invited someone over who lives all the way in California and been totally thrilled when they surprisingly agreed? Well that's the wonderful news about our October meeting.

Mr. Nicholas Gritzai, President of CyMed Ostomy Pouching Systems in Berkeley, CA is actually traveling hundreds of miles to be our next guest speaker. Wow! Cymed pouching systems are so innovative and practical that they have significantly improved the quality of life of many thousands of ostomates all over the US and Canada (in their own words) for two decades, and soon CyMed expects to continue their mission in many other parts of the world.

Nick says, "We at Cymed derive much genuine and rewarding human satisfaction from knowing the work we do is helping people who have often been through quite a lot and who deserve better, have richer and more meaningful lives. And it amazes (and humbles me) that a small company such as ours can produce such a valuable and important product that even the 'big boys' don't approach. That is why the ostomates who use it are so loyal. Honestly I've never seen customers more loyal to any product in my life.

The key Cymed innovation is the patented "MicroSkin" system, a very thin and flexible polyurethane film the pouch attaches to, that is then used to attach the pouch to the skin around the stoma. MicroSkin:

- * Adheres well and for long periods to the skin (without need to add glues, belts, etc.) thus greatly minimizing leaks and accidents and getting longer wear time,

- * Is very flexible so that when you move, bend

down, or stretch, it instantly adapts to those movements,

- * Is porous, which means it allows the skin to breathe life-giving oxygen and stay healthy for the long-term,

- * Is waterproof, allowing for swimming and even demanding athletic activities (with confidence)

- * Is low-profile under the clothing and comfortable, often allowing one to forget he even has it on"

If you would like to get a head start on learning about CyMed's wonderful products go to their catalog online at: <http://cymedostomy.com/catalog.pdf>

Coral Springs Ostomy Support Group

Coral Springs Medical Center's "Caring & Sharing Ostomy Support Group" meets on the 4th Wednesday of the month at 5:30 PM - 7:00 PM in. For more information, call Patricia Paxton-Alan, MSN, ARNP-BC, CWOCN, a cherished member of BOA's Medical Advisory Board.


SOME OF THE BEST BASIC OSTOMY HINTS

via The Right Connection, San Diego

Don't believe as if having an ostomy makes you less of a person or some freak of nature. There are lots of us and most of us are glad to be alive. Build a support system of people to answer questions when you have a problem. Consider our Ostomy Nurses and your officers who are listed in this newsletter.

Don't play the dangerous game of making your appliance fail by over taping or putting off a change. There aren't any prizes given for the longest wear time except accidents.

If your stoma is skin level or only a third of an inch high or less you **MUST** use a pouching system with convexity. Convexity is not an option but essential.



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CCFA Half Marathon

By BOA Member Paula Segal

When I was approached by Rachel Backoff, mentor and fund-raising coach from the CCFA (Crohn's & Colitis Foundation of America) to participate in the Napa to Sonoma California half marathon, I thought "why not"? Running a half marathon (13.1 miles) was always on my bucket list of things I wanted to accomplish in my life. I had traveled 68 counties on all but one continent, but never ran a half marathon. I was in good shape at the time, Crohn's in remission, and was working out at the gym 2-3 hours daily.

I attended an informational meeting in January 2010 at Whole Foods in Boca Raton, and found myself signing up for this wonderful challenge, to raise \$4,000 and run a half marathon in hopes in finding a cure for Crohn's and Colitis. Little did I know that both would REALLY be a challenge!

For the 6 months following the meeting, I trained with a CCFA designated coach every Saturday morning, awakening at 3:30 am to beat the humidity and heat. I, along with 17 other people, ran up and down A1A with one thing in mind, we were going to cross that finish line and raise enough money to

make an impact. I also trained on my own at the gym, running 6-9 miles two times a week.

I designed a website for contributors to donate to the CCFA and sent out many emails with the link to my website, explaining that 80% of their donation would go towards research to find a cure. I spent several evenings hosting fund-raisers at various restaurants and clubs selling raffle tickets for gift cards that other restaurants and establishments so generously donated for the cause. Of course, my *Broward Ostomy Association* group chipped in with a total just shy of \$200.

Finally, the day came to board our plane to San Francisco that July 17, 2010. There were 20 of us, mostly running and a few family supporters. We



met up with the other 800 CCFA runners in Santa Rosa and shared many stories, laughs and picture taking. There was a great sense of bonding and connection between us all. We knew we were all in California for the same cause.

The morning of the run we woke up at 3:30 am to get our group picture taken and to board the bus to take us to the start line at one of the local wineries. It was 53 degrees out and sunny. We all started out together and it was a beautiful site to look back and ahead to see the long snake that we formed, knowing that we all were running for a cure for Crohn's and Colitis.

After mile 3, the endorphins kicked in for me and I looked around and said to myself, this is such an awesome experience to be running amongst the green grape vineyards of Napa California.

Many had written on their jerseys of whom they were running for. I was running in honor of myself and all the other thousands of people with Crohn's. It truly was an uplifting, encouraging experience to see so many people who cared and wanted to make a difference. I crossed the finish line at the central plaza in Sonoma after 2 hours and 40 minutes of running, exhausted, dehydrated and elated.

Even though I did not raise all the money that I had wanted to (I raised \$3,000 in total), I had a memorable experience that I will take with me for the rest of my life.



participate in the annual local walkathon each April, raising funds and raising awareness in hopes that one day there will be a cure for Crohn's and Colitis.

I want to thank everyone who helped support me with my fundraising. It was quite challenging but fun. I have accomplished what I have always wanted to do, run in a half marathon, and I will continue to

Passing the Torch

The Phoenix Legacy Society



UOAA invites us to imagine a young girl. At age 16 she will be diagnosed with Crohn's. At 28 she will agree to an ostomy. She will need the support and comfort that UOAA members provide. In 2038 will there be a support group to help her? It's up to The Phoenix Legacy Society.

George Salamy, Chairman of the UOAA Board of Trustees writes, "You support the values, mission and vision of UOAA, now help us ensure the long-term strength of the organization. Future generations will continue to need emotional support and education. Become a Founding Member of The Phoenix Legacy Society now. You can express your commitment and support by:

- Pledging a bequest in your will or trust
- Naming UOAA as a full or partial beneficiary of your life insurance policy or retirement account.

As a Founding Member you will receive (anonymity is also respected):

- A certificate of appreciation from the Chairman of the Board of Trustees
- Recognition at the 2011 UOAA Conference
- Recognition in the summer 2011 issue of The Phoenix Magazine
- The quarterly President's update with information on advocacy and programs.
- A lifetime subscription to the Phoenix Magazine

If you have already arranged for a bequest or planned gift for UOAA please notify us. We will honor your support and welcome you as a Founding Member. If you are considering a planned gift to UOAA, we can help you and your advisors complete the necessary paperwork that benefits your estate and clearly states your intention to help your fellow ostomates. Contact Joan at 800 826-0826.

Memorial Hospital West

Ostomy and Wound Care Services

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:

- Stoma site selection
- Ostomy product selection
- Treatment of peristomal skin complications
- Peristomal hernia belt fitting
- Complex fistula/tube management

For information or to schedule an appointment, please call (954) 844-6834. Ostomy and wound care services are available every Thursday from 1pm to 3pm at our outpatient clinic.

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Basic Hints *continued from page 4*

Any ostomy product that has the word “paste” in its name is NOT paste, it is caulking. It has NO adhesive properties at all. Even nurses sometimes don’t know this.

Don’t wait until you see the bottom of your supply box before ordering more. Always count on delays in shipping, holidays, etc. when calculating what is needed. Right after you’ve applied a new skin barrier wafer, place your hand on top for at least 10 minutes. The wafer is heat activated so that the warmth from your hand will greatly enhance its adhesive properties.

Zip-lock sandwich bags are useful and odor-proof for disposal of used ostomy pouches.

Don’t get hung up on odors. There are some great sprays and some internal deodorants...Remember—everybody creates some odors in the bathroom. Don’t feel you are an exception.

Hydration and electrolyte balance is of vital importance. Be sure to drink enough fluids to maintain good hydration, ileostomates especially. Read and learn all you can about ostomies. You never know when you may find an opportunity to educate someone about the life-saving surgery that has extended so many lives. Learn to be matter of fact about this and never embarrassed. Few folks get out of this life without some medical problems and unpleasant situations with which to cope. You may be amazed at how people will admire your adaptability and courage.

In the beginning after surgery, almost every-
one experiences some
depression. If you fit
into this category, you
are certainly not alone.
But it need not be a
lasting condition. Try
something as simple
as walking...long
walks. If the depres-
sion seems to linger,
don’t be afraid or
ashamed to seek help.



There is help out there! The bottom line is— We are alive! In other times, in other countries, we might not be. Medicine and techniques today have given us an opportunity to experience this second chance. The most important part of you as a human being has not changed.

Minutes ~Sept. 5th 2010

The Labor Day weekend meeting began promptly at 1:30 p.m. with President Wendy welcoming everyone back after the summer break. First time guest Stephen read the Ostomy Prayer. Other first timers were welcomed including Zippy, David, Alan and guest attendant Brenda. Wendy reminded everyone that even though we don’t meet over the summer, our 24 Hour Hotline is still available. Wendy acknowledged the continued services of WOC nurses Amparo Cano and Eula Fahie-Romero.

Our association’s *Broward Beacon* newsletter is now available online at our website www.browardostomy.org. It was noted that last month’s Beacon has a UOAA Travel Communication Card on page ten. Everyone is encouraged to cut it out, complete it and laminate it. It is useful for simplifying passage with ostomy supplies thru Transportation Security and provides emergency medical information. Wendy noted that part of the card states that the holder needs access to the restroom NOW due to our medical situations.

Wendy gave out 20% off certificates for the Miami Seaquarium, good thru 12/17/10. For each discounted admission with the coupons, our Broward Ostomy Association will receive \$5.

The UOAA is sending Wendy to Washington, D.C. for the Chapter Advisory Board.

Ren placed on each table a signup sheet for a UOAA Career/Work Database Project. These forms are a national attempt to compile a database of members who desire to share their experiences regarding how they continued to work and adjusted to their employment after their operations. Participation is completely voluntary.

Amparo won the 50/50 door prize this month.

Minutes *continued from page 9*

Cosmic payback for all the good she has been doing! First VP and Program Co-Chair Amy introduced the speaker for the month, Amparo Cano who will report on the Youth Rally. She and Michael Mendoza, who we sponsored as a Counselor-in-Training, attended the event which was held July 12th – 17th this year at Xavier University in Cincinnati, Ohio. Before Amparo took the stage, Wendy presented a video compilation of pictures (with music) documenting many of the events held at the Rally.

Amparo thanked everybody for our help in enabling her and Michael to attend. The main focus of the Rally was to provide educational and psychosocial support for youths ages 11 to 17 with ostomies, urinary, or bowel disorders. Returning campers are encouraged to form lasting relationships with each other, as the objective for many is to be drawn out from isolation. There are strict guidelines of conduct to protect the attendees and rarely must an individual be let go for behavioral issues. There were about 15 nurses and 135 campers attending, and the airport coordinator must deal with about 200 people arriving at nearly the same time.

Amparo's role as was to reinforce ostomy routines as well as deal with other medical conditions of the youths. Nine attendees were assigned to her care. She offered hygiene and health education, facilitated classes and group sessions, and assisted as needed with bowel program, dressings, and medications.

For all, objectives of the Rally participants included improvement of communication, learning about and understanding themselves and others in similar situations, increasing self-confidence, and meeting role models. A motivational session was given by Rob Hill, a well known ostomate and accomplished 7 summit mountain climber. Another motivational speaker was a professional bullfighter.

On Fitness Day, attendees visited the University of Cincinnati for a day of dance, karate, and use of the fitness center equipment. At King's Island Amusement Park Michael rode a roller coaster for the first time in his life. In a Talent show there were magicians, singers, tap dancer, a flutist, and a comedian, among others. A self-esteem skit was performed by all counselors and Counselors-in-Training. There

were medical sessions, a group counseling session, and finally, graduation of 18 year olds.

At the conclusion of Amparo's presentation, Wendy presented her with the traditional speaker's brownies and hoped that Amparo would be able to go to the Youth Rally again next year. Betty talked about how important it is to help out with our youth, since contacts like that were not available to her growing up. When she later was a counselor at a Rally, she learned a lot from the kids.

Amy announced that Nick Gritzai of Cymed, a manufacturer of ostomy supplies, will be our next speaker in October. In November, Rob Seaman of ConvaTec returns to speak about a "revolutionary new product." Amy also requested members contact her if they have request for a speaker or would like to have a topic covered. The only requirement is the topic should be ostomy related. The meeting was brought to a close by Wendy at 2:33 p.m.

Respectfully submitted,



Bill Wilson,
Recording Secretary

Ostomy Products Allowed by Medicare

Pouches (Closed), 60 per month; Pouches (Drainable), 20 per month; Pouches (Urinary), 20 per month; Wafers (4 x 4), 20 per month; Wafers (6 x 6), 20 per month; Wafers (8 x 8), 20 per month; Stoma Cap, 31 per month; Lubricant, 4 oz. per month; Irrigation cone/bag, 1 every 3 months; Irrigation Sleeve, 4 per month; Stomahesive Paste, 4 oz. per month; Adhesive, 4 oz. per month; Adhesive Remover (liquid), 8 oz. every 3 months, Adhesive Discs, 10 per month; Convex Inserts, 10 per month; Ostomy Belt, 1 per month; Appliance Cleaner, 16 oz per month; Skin Barrier Wipes, 3 Boxes/50 every 6 months, Ostomy Deodorant, liquid or tablet, no set allowable amount; Drainage Bottle, 1 every 3 months; Drainage bag, 1 per month; Ostomy absorbent packets, 90 per month.

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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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- 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).



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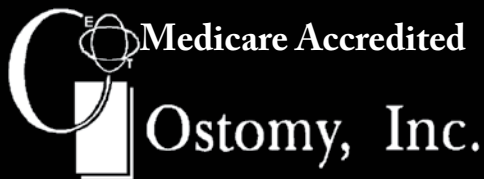
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