



*These UOAA UPDATES are our way of communicating what is happening to you, our members. It is our hope that this information is being passed on to your members, either by **including some of the news in your newsletters** or by **discussing it at your local support group meetings**. People continue to ask, "What is UOAA doing for m?" and this is our way of answering this time-old question. We continue to look forward to working with you and to being an active resource to ensure your success.*

SEPTEMBER 2008

LATE BREAKING NEWS!

Keep current with the **UOAA blog**.

Thanks to the efforts of Kristin Knipp, UOAA now has new way to communicate with you .. we have a blog. For the uninitiated, a BLOG = a shortened form of **web-log**. It's our way of bringing you up-to-the-minute news about happenings within UOAA. In addition to the general blog there will be one concerning advocacy matters, and others as time goes along.

You can find it at www.uoaa.org in the left-hand navigation menu, or go directly to <http://uoaa.wordpress.com/>

THEMED PHOENIX PATIENT RESOURCE MAGAZINES

UOAA hit a homerun with this project!! I am most pleased to report that the 4 **Phoenix Patient Resource magazines**, i.e. those written specifically for new Colostomy patients, new Ileostomy patients, new Urostomy patients, and new Continent Diversion patients, have met with overwhelming approval by Hospitals and medical professionals throughout the US. Designed to be part of the information given to new patients by ASG members making visits, many WOC Nurses have requested copies in those areas where there are no UOAA affiliates. The cost of these magazines is being underwritten by UOAA as a service to its affiliates and the ostomy communities they serve. While supplies last, if you want to receive additional copies, e-mail Joan McGorry at oa@uoaa.org. Because the quantities are limited, orders may not exceed six copies of any one themed magazine per order, and, there needs to be a minimum of 2 months

between repeat orders. There will be a \$ 5.00 charge per order to cover shipping expenses.

ASG LEADERSHIP ADVISORY BOARD

The ASG Advisory Board, which presently consists of the ASG Leadership Award recipients, will be increased to 8 members this Fall when the MBoD appoints 4 more members. These new members will serve a two-year term commencing January 1, 2009. In order to identify candidates for the ASG AB, members of the MBoD, those presently serving on the Advisory Board and the members of UOAA's Board of Trustees have been asked to communicate with people they think would serve well at the national level. Those ASG leaders who are contacted, who say "Yes, I am interested in serving", will be asked to send a letter to our Office Administrator, Joan McGorry, by November 1st, describing why they should be selected. These letters will be distributed to the MBoD, and the top 4 judged to be most qualified by the MBoD at its November 21st Annual Meeting in Cherry Hill, NJ, will be appointed. If you are interested in serving on this Board of Advisors, and have not been asked by someone else, send me an e-mail (kenaukett@uoaa.org) and I will be happy to throw your hat into the ring (wow, do they still use that expression? ... shows my age!)

OFFICE STAFF

Have you called the 800-826-0826 number lately expecting to speak with Joan, only to find out there was someone else on the other end? Earlier this year Joan hired an assistant, Linda Torres, to work with her part time serving UOAA. Linda also helps Joan with mailings and will be very active as we start to prepare for next year's conference in New Orleans.

UOAA has entered into a contract agreement with Rita Hillis, a retired WOC Nurse (RN, BSN, CWOCN to be exact) who will answer the questions of people who call the 800 # looking for some stoma-related advice. If a WOC Nurse cannot be identified who lives near the caller, contact information will be given to Rita. This is yet another free service UOAA provides to the ostomy community.

TRAVEL COORDINATOR

With the cost of travel headed upwards, UOAA has engaged the services of San Diego Travel Group to ensure that the members of the MBoD get the best “deals” available when their duties require travel. Serving as our coordinator will be Allannah Feeney, a person who has a long history of working with UOA and the Youth Rally. To her credit, over the years arranging flights for the young rally campers, she has never lost one!

If you have need for a Travel Coordinator, if you want to plan “Carefree Vacations”, Allannah would be more than happy to work with you. You can reach her at 877-INFLIGHT (463-5444) or by e-mail at afeeney@sdtg.com. There is a nominal fee for her services, but when you are faced with a cancelled flight in an empty airport, it is most comforting to know she is there for you.

UOAA ANNUAL AFFILIATION FEE

At its meeting held on August 22nd and 23rd, the UOAA Management Board of Directors voted to keep the Annual Affiliation Fee at the same rate of \$ 2.00 per member or \$ 25.00 for those support groups that report “no members”. Payments for 2009 at due January 1st, 2009.

In another action the MBoD determined that those ASGs that have not paid their 2008 affiliation fee, will have information about their group removed from the UOAA website on January 1, 2009, and their listing in *The Phoenix* magazine removed from the support group listing beginning with the Winter 2008 issue. If the group chooses to pay the fee, their listings will be reinstated. Notes will be added to the website and magazine advising persons not

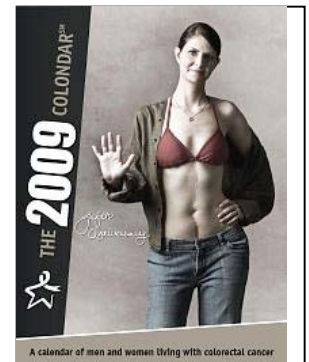
finding a listing for a group in their area to contact the UOAA Office for further information.

Copies of the minutes of the August MBoD meeting can be obtained by e-mailing Joan McGorry at oa@uoaa.org.

2009 COLONDAR

Again this year UOAA is shown its support for the colon cancer awareness initiatives of The Colon Club by sponsoring a page in its 2009 Colondar. Sale of these calendars, featuring models under the age of 50 who are colon cancer survivors, is a major fund raiser for The Colon Club. If you purchase one or more from UOAA, it helps underwrite our sponsorship fee. Go to www.uoaa.org to see the 2009 Colondar that is now for sale ... still \$ 15.00

These make excellent gifts for speakers, door prizes, and as a gift to those WOC Nurses and Colo-rectal surgeons that make up your group's medical advisory board.



VOLUNTEERS NEEDED

One of the projects that UOAA is undertaking is the production of a short DVD designed to inspire and encourage new ostomates, helping them to realize that it is possible to live a happy and productive lifestyle with an ostomy of any type. We are looking for volunteers of all ages and ethnicities who are willing to participate in this video. Their role would be to show, by example, either their employment, hobbies, outside interests or volunteer work and thereby demonstrate to the general public that having an ostomy does not prohibit a person from living a life of quality, productivity and happiness.

If you are interested in being a participant in this project, please send an e-mail to Aileen Gould at soulful@verizon.net with your contact phone number and a brief synopsis of your personal story, indicating why you feel you would be a good candidate for this DVD. Please understand that we expect to receive many more applications than we can include in this brief video, so do not take it personally if we cannot include you. In Aileen's words, “We know that WE ARE ALL EXCEPTIONAL! Thank you.”

GYGIG 2008 TEXAS RIDE – SIGN UP NOW!

There is still time to gear up for the ride of your life! [Join Get Your Guts in Gear](#) for its 3rd annual Texas Ride, October 17-19, benefiting several great organizations including CCFA, **UOAA** and The Colon Club. Register now to ride this scenic route through central Texas. It begins near LaGrange and ends near Austin, winding through the Lost Pines, the Guadalupe River, and the Hill Country.

Whether you are an experienced cyclist looking for a great ride or a novice rider who is affected by one of these diseases, you'll enjoy GYGIG's scenic, fully supported rides. Don't ride a bike? Become a part of the GYGIG community by joining the all-volunteer crew, which is an integral part of each Ride.

Every pedal stroke of the ride is an empowering experience, riding for those who can't and bringing together those affected by the disease or surgery for something positive. Add your strength to the 1.4 million Americans in the Crohn's and colitis community and the 600,000 ostomates while raising funds and awareness for, and about the organizations that serve these communities



The GYGIG Rides span three days, and averages 70 miles per day. The Rides are fully-supported and include two overnight camping stops to relax and recharge your engines with food, friends, hot showers, and even towel service.

For more information and answers to FAQs, please visit www.IBDride.org. Want to talk to someone about how you can get involved? Call GYGIG at 866-9iGOTGUTS (866-944-6848). Don't miss this opportunity to join GYGIG this year!

MID ATLANTIC REGIONAL CONFERENCE November 21st – 23rd, in Cherry Hill, New Jersey

The Delaware Valley Regional Taskforce, a consortium of UOAA ASGs in the Eastern Pennsylvania, Southern New Jersey, Delaware area, will convene a Regional Conference on Friday night, **November 21st** through Sunday morning, the **23rd** at the **Holiday Inn in Cherry Hill, New Jersey** (15 minutes from downtown Philadelphia).

Friday evening will feature a get-acquainted reception; Saturday's program includes educational workshops, a product exhibition and free stoma clinic and an optional evening Banquet. On Sunday morning, there will be a Program for Support Group Leaders to discuss "What do we have to do to get the Medical Community to notice us??"

The keynote speaker for the Saturday educational program will be **Scott Ellis**, Great Comeback Awardee for 2007. The day will include workshops of interest to all ostomates and those with continent diversions, a product exhibition, and a free Stoma Clinic staffed by local WOC Nurses. The evening's banquet will feature entertainment by comedian, author, and ostomate **Brenda Elsagher** ... an evening with Brenda is a must!

Mark the **November 21-23** dates on your calendars now. For detailed information and a registration form visit www.ostomysnj.org

UOAA's 2nd NATIONAL CONFERENCE

UOAA's 2nd National Conference ... "NC-2" ... will be held on August 5th through the 8th, 2009, at the Sheraton New Orleans Hotel on Canal Street right off of the famous French Quarter in historic downtown New Orleans www.sheraton.com/neworleans

A Conference planning meeting was held at the New Orleans hotel on August 21st through the 22nd. The committee is glad to report that New Orleans tourist facilities have come a long way back from the devastation of Katrina – and even happier to report that there was little damage from Gustav.

As a result of this meeting I can share with you the following Programming highlights:

- Wednesday afternoon: A 1st Timers' Session and Reception with UOAA Leadership
- Wednesday night: *First Night* opening ceremonies followed by a Taste of New Orleans Gala Ice-Cream Social with "Beignets" and festive local entertainment.



- Thursday morning will feature a series of "basic" concurrent workshops targeted at ileostomates, colostomates, urostomates and those with continent diversions using "Ask the Dr.", "Ask the WOCN" and "Living With ..." panel formats.
- Thursday afternoon the Exhibit Hall will open followed by the traditional **ConvaTec** surprise party.
- Friday morning the Exhibit hall will be open until noon, after which is our Recognition Award Luncheon
- Friday afternoon we will have general workshops plus workshops with content aimed at the 30+, the teens, Young Adults and Continent Diversions. And of course there will be a three-day mini conference Thursday thru Saturday for our youngest attendees and their parents, the Pull Thru Network coordinated by Bonnie McElroy
- Friday night is a free night to explore and enjoy the "Big Easy".
- Saturday will see the workshops continue and we will have a great New Orleans style banquet.

Sound like fun – we guarantee it will be! It is not too early to start planning to attend **UOAA's NC-2** now. Of special note, an invitation has been extended to, and accepted by the International Ostomy Association's **20/40 Focus** to participate in this event, as they celebrate their 10th Anniversary. Young ostomates from around the world will be meeting with the UOAA's YODAA affiliate in what should prove to be a most exciting event. The sharing of information and global networking make this a "must attend" gathering.

GREAT COMEBACKS AWARDS

Now in its 24th year, the Great Comebacks[®] Program annually recognizes people who have fought courageous battles against Crohn's Disease, ulcerative colitis, or who have undergone ostomy surgery. Since 1984, the men and women who have received this Award have served as role models to thousands of people across America. UOAA is proud to have been asked to serve as a sponsor of this great program.

One of the events we have planned for NC-2 is a workshop featuring as speakers members of our UOAA family who are honored recipients of a Great Comebacks Award, including our current Vice President, Bob Baker; Director, Charlie Grotevant; Teen Network Chair, Jude Ebbinghaus; Broward Ostomy Association President Wendy Lueder; and, Abby Ryan who received an Ina Brudnik Scholarship Award for those of college-age. Abby has also agreed to serve as our Friday Luncheon speaker.

If there is someone in your support group that you feel is deserving of this national recognition, I encourage you to visit www.GreatComebacks.com and submit a nomination for them or, for that matter, for yourself!

IN CONCLUSION

September 11, 2001 ... let us not forget the events of that tragic day, and how the USA, like our Phoenix, rose from those ashes of despair and regained the spirit that makes this country the greatest nation on God's green earth.

Ken Aukett - President, UOAA