



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 me, 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.

DECEMBER 22, 2008

FALL 2008 ELECTION

As a result of the election that concluded on November 30th, one of our incumbent Directors, **Lynne Kramer**, was elected to her second term, and the Chair of our ASG Advisory Board, **Bob Parish**, was elected to his first term. I wish to thank both Tillie Horak and Katie Torango for their interest in serving at the national level and feel confident that we will be hearing from these two dedicated women again!

Since we began our UOAA planning activities in 2005 one man has been a quite, yet forceful presence in our deliberations, development and implementation of our new organization's mission. Charlie Grotevant is leaving the MBoD by year end. His negotiation skills and all-knowing smile will be missed!

UOAA MBoD APPROVES THE OPERATING BUDGET FOR 2009

At its Annual Meeting, convened November 20th and 21st at the Holiday Inn in Cherry Hill, New Jersey the MBoD passed a FY 2009 Operating Budget of \$ 414,500. Increases in the 2009 Budget over that of 2008 were a result of one-time expenses associated with the projects UOAA embarked on in 2008 that are scheduled to be completed in 2009 and the fact that a National Conference will be convened.

ANNUAL AFFILIATION FEE REMINDER

The deadline for payment of your 2009 Annual Affiliation Fee is **January 1st, 2009**. The fee remains unchanged at \$ 2.00/member in your ASG. For those groups that have reported "no members" the fee will be \$ 25. Groups that do not pay the AAF by **May 1st, 2009** will have their contact information removed from the directory in *The Phoenix* magazine and from the directory

maintained on the UOAA website. If your group cannot afford to pay the AAF but wishes to remain as a member of UOAA, please contact Joan McGorry at oa@uoaa.org for the necessary accommodation.

It should also be pointed out that ASGs that had their IRS 501(c)(3) status as a Chapter of UOA and have not taken action to apply for their own independent IRS Charity Status, or enrolled under UOAA's umbrella, can no longer legally provide tax deduction coverage to their donors now that UOA has finally ceased to exist as a corporate entity (this happened early Fall 2008).

CONSTITUTION AMENDMENTS

UOAA, as a dynamic organization, has an ongoing commitment to make those policy and procedure changes that will best serve its long term interests. In order to encourage people to volunteer as leaders at the national level, the Management Board of Directors felt that if the term of the President, President-Elect and Vice President were changed from three years to two years, more people be able to serve. In addition it was felt that the Vice President should have the opportunity to be re-elected to a second consecutive term as is the case for the Secretary and Treasurer. These recommendations by your MBoD were written as a **Constitution Amendment** that was sent out late last week to the ASGs for their approval. ASGs have until **February 28th, 2009** to make their opinion known.

CHANGE IN TITLE

For your information, please note that **Joan McGorry**, who provides contract administrative services to UOAA, now has the title of **Director of Administrative Services**.

WOC NURSE OF THE YEAR AWARD

It's not too early to start thinking about that special person in your group that you would like to nominate for UOAA's **WOC Nurse of the Year Award**. The necessary forms will be sent to you in an upcoming UPDATE. The Award will be presented at the WOCN Society's Annual Conference that will be held on June 6th- 10th in St. Louis.

ASG LEADERSHIP AWARDS

Once again **ASG Leadership Awards** will be presented to 4 outstanding volunteer support group leaders. Is there someone in your group who deserves to be in the national spotlight? This year's recipients will be invited to be UOAA's guests at the National Conference in New Orleans where the Awards will be presented at Friday's Recognition Luncheon. I will be sending you Award details in the near future.

C.A.R.E.S. PROGRAM

This past November you were notified about UOAA's **Conference Attendee Reimbursement of ExpenseS** Program. UOAA will provide approximately 10 deserving members ASG members with up to \$ 650 so that they can attend the New Orleans Conference next August. Applications from qualified applicants are due back in the UOAA Office by March 15th, 2009. If you need additional application forms or information, please don't hesitate to communicate with me.

COLONDAR

UOAA is working with **The Colon Club** to promote colon cancer awareness.

As a result of our sponsorship of a "month" in their unique calendar, UOAA received 500 "**Colondars**" that we are offering for sale at the fixed rate of \$ 15.00 each.

Each of the monthly models in the "**Colondar**" is a colon cancer survivor under the age of 50, and several have an ostomy! We feel that a **Colondar** will make an excellent door-prize for a monthly meeting, a gift for a speaker, or just for

someone who wants to promote colon cancer awareness.

To get the full story go to the UOAA website ... www.uoaa.org ... and check out the **2009 Colondar** that is now for sale!

GYGIG 2009 – RIDERS NEEDED!! What Is Get Your Guts In Gear?

Get Your Guts in Gear, Inc. is a small independent charity created to raise awareness about Crohn's disease and ulcerative colitis, and to raise funds for other charities that support research, education, and patients who are living with IBD or ostomies. GYGIG's mission also includes empowering individuals affected by Crohn's, Colitis, or ostomy surgery through participation in large-scale athletic events in a supportive community atmosphere.



As a benefactor of the Get Your Guts in Gear rides in 2007, UOAA received a check from GYGIG for \$ 63,840 !! However, in 2008, in part due to the economy, and in part to a drop-off in riders, it is projected that UOAA will received less than \$ 25,000. **This is where you come in ... RIDERS FOR THE 2009 RIDES ARE NEEDED.** These rides will take place as follows: Hudson River Valley, NY on June 12-14; Pacific Northwest (Seattle area) on August 7-9; and, in the Mid West this Fall (details yet TBD)

For more details about the GYGIG exciting, challenging and beneficial program, visit <http://www.ibdride.org/>

HOW ABOUT THAT UOAA BLOG???

Did you hear about the new Social Security Compassionate Allowances for the seriously ill and disabled, or about the FDA warning about bowel prep products? How about the new Medicare policy on urinary catheters, or the improvements to the Americans with Disabilities

Act? If you are a regular visitor to the **UOAA blog**, you can answer "YES". This is a place where we can inform you about a variety of things that will affect your life, as they happen. We hope you will stay tuned to <http://uoaa.wordpress.com/> and share the news you see there with other members of your support group.

NEWS FROM NEW ORLEANS



With activities planned from Wednesday through Saturday, let's take a look at what will be happening early on

Wednesday, August 5, 2009

If you are new to the Conference experience you will want to attend the "First Timer's Orientation" followed by a reception exclusively for you where you can get to know and network with other "first time conference attendees" and benefit from a sneak preview of what UOAA has planned for you educationally, socially and fun-wise.

*After dinner (on your own), the **Opening-First Night Ceremonies** will begin at 7:00 PM. This will be followed by a **Hollister Incorporated** sponsored "Sweet Taste of New Orleans" social, featuring make-them-yourself ice-cream sundaes, King Cake, and those sinfully good infamous sugar coated beignets.*

Thursday, August 5, 2009

The morning will feature a series of 4 concurrent educational workshops, (one for Colostomy, one for Ileostomy, one for Urostomy and one for Continent Diversion Procedures). The series will include "Ask the Doctor, ask the WOC Nurse, and "Living with" panel workshops.

*In the afternoon there will be Spouses workshops and at 2:00, the **Exhibition Hall Opening** where you will have the opportunity to talk with representatives of all the ostomy product manufacturers and major distributors. At 7:00 PM we will once again be the guests of **ConvaTec** and participate in their traditional **Evening Gala** ... an evening of fine food and entertainment.*

FROM MY IN-BOX

"Dear Ken:

I recently had an idea regarding the UOAA Virtual groups that I wanted to share with you.

When a new ostomate or prospective ostomate is introduced to the world of Ostomy by a visitor, physician, surgeon or nurse, they are probably referred to the local support organization or if they are lucky, to the UOAA website. Therefore, they have a place to go to in order to seek support, ask questions, etc. However, there are times when that person feels more of a need to relate to their own kind, such as being a teen, being under 40, being gay or lesbian, having a Continent Diversion, etc. This person has no way of knowing that a Virtual group exists which can be of interest to them.

Each ASG that publishes a newsletter, probably publishes the names and contact information of its officers, directors, and sometimes the telephone number and website for the UOAA as well as other Ostomy related links. I think that it would be a great idea if all of the ASGs would publish the name and contact information of all Virtual groups in their newsletter along with their local contact information.

A change of this nature should allow more people to learn about the Virtual groups faster and help these groups to grow in numbers, strength and effectiveness.

Thanks, Fred Shulak”

Fred, as a follow-up to your great suggestion, I pass along the following information:

- Pull Thru Network (Parents of children with bowel and urinary dysfunctions): Bonnie McElroy ... 205-978-2930
- UOAA Teen Network: Jude Ebbinghaus ... 860-445-8224
- GLO Network: Fred Shulak ... 773-286-4005
- Young Ostomate & Diversion Alliance of America (YODAA): Eric Eng ... 714-904-4870
- Thirty Plus: Kathy DiPonio ... 586-219-1876
- Continent Diversion Network: Lynne Kramer 215-637-2409

UOAA AFFILIATES

For those of you who are keeping score along with us, with the addition of the Ostomy Support Group of Prince William County, Virginia, UOAA now has **276 ASGs!**

IN CONCLUSION

Just today I received an e-mail that has been around the world probably more times than that jolly old elf in the red suit ... but, as 2008 comes to a close, the expressed sentiments are certainly worth repeating in the off-chance that you have not read them:

My Wish for You in 2009

May peace break into your home and may thieves come to steal your debts.

May the pockets of your jeans become a magnet for \$100 bills.

May love stick to your face like Vaseline and may laughter assault your lips!

May happiness slap you across the face and may your tears be that of joy

May the problems you had, forget your home address!

In simple words

May 2009 be the best year of your life!!!

Linda and I wish you a happy, healthy

NEW YEAR!!

Ken Aukett - President, UOAA

