



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.

JULY 9, 2009

□ NEWS FROM NEW ORLEANS

If you have not reserved your room at the Sheraton Hotel yet, you are almost out of time. Monday, **July 13th** is our room block cutoff date. So book today by calling 800-325-3535 and use the Group Code: "UOAA" to get the \$ 109/night Conference rate. Rooms booked after the 13th will be available at the Conference rate only if the hotel has any unsold rooms for the August 5 – 8, 2009 dates.

Near the Conference Registration Desk on the Hotel's 3rd Floor UOAA will have a table where the following items will be sold: Colondars, UOAA Luggage Tags, Stress Balls, Mardi Gras Masks and, introducing the new UOAA Organizational Pin and the Official UOAA Conference Limited Edition Collector's Pin.

Also, in this same area, orders will be taken for the free Ostomy Patient Resource magazine designed to be part of the information given to all new ostomy patients ... a valuable addition to your ASG's Visitors Packets. And, two authors will be with us to sign copies of their books.

Conference highlights include:

- 1st Timers Orientation and Reception sponsored by **Coloplast**
- 1st Night Ceremonies featuring Tim Mitchell, followed by the **Hollister** sponsored "Sweet Taste of New Orleans" social
- Free Stoma Clinic
- The Colossal Colon Exhibit sponsored by **Edgepark**
- Exhibition Hall
- **ConvaTec's** Traditional Gala
- ASG workshops

- **Nu-Hope's** infamous "Fun Run"
- Recognition Luncheon with Abby Ryan
- Great Comebacks Awardee Session
- Presentations by Brenda Elsagher and Rob Hill
- Special "Teen Day" and Pull-Thru Network Programming
- Sneak Previews of the new UOAA Visitor Training DVD and the new PR DVD showing the quality of life that people with ostomies can attain.
- A Fashion Show sponsored by **Dillard's Department Store, C3Life, Ostomy Secrets** and **Vanilla Blush**
- Educational Workshops targeted for General, 30+, YODAA, CD and GLO audiences
- A Masked Ball Closing Banquet



YOUR ATTENTION PLEASE!!

The deadline is fast approaching for this year's award process, but there is still time to enter. If you would like to share your story and offer inspiration and encouragement to others, or you know someone who would like to share their story, I encourage you to visit the "US Awards Program" page at www.GreatComebacks.com and submit a nomination for yourself or others by **July 15, 2009**. Eligible entries received after July 15, 2009 will be considered as part of the 2010 process. If you have any questions, please contact Etanjalie Ayala at 212-445-8225 or eayala@webershandwick.com

- **LET YOUR VOICE BE HEARD!**

As I have previously communicated on several occasions in the past, Jennifer C. Jaff, Esq., Executive Director of Advocacy for Patients with Chronic Illness, Inc. has entered into an agreement with UOAA wherein she will provide legal counsel to members of UOAA's Affiliated Support Groups who are experiencing discrimination issues because of their ostomy, be it in the form of social discrimination, or discrimination in the workplace. Jennifer stands ready to advise you of your rights and assist you in the development of a plan of action. This service is provided **free** to any inquiring ASG member. (As a service to its members, UOAA underwrites the cost of these services.)

Jennifer Jaff may be reached at her home office in Farmington, Connecticut by phone at (860) 674-1370, by fax at (860) 674-1378, by e-mail patient_advocate@sbcglobal.net or at her website www.advocacyforpatients.org

Recently the following communication was received from Ms. Jaff.

"Have you always wished that you could tell your health care story? Here's your chance!

We, the Advocacy for Patients with Chronic Illness, Inc. and the University of Michigan Center for Managing Chronic Disease have been awarded a grant by the National Institutes of Health (NIH) to conduct a study of patients with chronic illnesses to study the obstacles facing the chronically ill and caregivers, interventions that do and do not work to surmount those obstacles, and ways in which the work done by the NIH, including research and clinical trials, may be helpful to patients with chronic illnesses. With the help of twelve patients and caregivers, we have drafted a survey which is available online at <http://chronicdisease.survey.sgizmo.com>.

If you have a chronic illness such as Crohn's Disease, ulcerative colitis, rheumatoid arthritis, fibromyalgia, multiple sclerosis, immune deficiency, or other chronic illness, or are a caregiver of someone with a chronic illness, are at least 18 years old, and would like to take the survey, please do so. If, for

any reason, you are unable to take the survey online, or you would prefer to be interviewed by telephone, or if you have any questions at all about the research, please contact Jennifer Jaff at (860) 674-1370. She will answer any questions you may have, provide more details about the study and arrange for an interviewer to call you to schedule the telephone interview at a time convenient to you. Any services you or the person you care for may receive from Advocacy for Patients will not be affected by your participation or decision to not participate.

Thank you."

□ **ASGs, UOAA and THE IRS**

At the present time there is still a misunderstanding by some of UOAA's Affiliated Support Groups about the IRS 501(c)(3) Charity Status, the need to have this status, and the option to enroll in UOAA's Group Exemption and take advantage of UOAA's umbrella coverage. In the near future I will provide a list of those ASGs that are presently enrolled, and those ASGs that have elected not enrolled because they think they are still covered by the now defunct UOA. The paperwork and actions required to align with UOAA are minimal, and the benefits to you are most beneficial.

□ **IN CONCLUSION**

I look forward to greeting many of you in the very near future in New Orleans. Our Conference Planning Committee has worked hard to put together four days of activities that will not soon be forgotten.

To those of you that I will not be able to greet, have a great summer, stay well and know that the services you are providing to our fellow ostomates are really, really appreciated! Thank you!

Best wishes for now,

Ken Aukett