



*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.*

**MAY 30, 2007**

## **IMPORTANT ISSUES:**

### 1) **ROOMS AT THE MARRIOTT**

If you have tried to reserve a sleeping room at the Lincolnshire Marriott for our conference by dialing **Marriott reservations at 800-228-9290**, and if you have been told that there are no rooms available ... they are wrong ... **rooms are available!**

- Rooms are available from Wednesday night, August 15<sup>th</sup> through Saturday night, August 18<sup>th</sup> at **\$ 129.00/night**
- Rooms are available on Tuesday and Sunday nights, but at a much higher price.
- When making your reservation state that you are attending the United Ostomy Associations of America Conference ... try using **Code UTTA**

Initially UOAA blocked 100 rooms. When these were sold out our room block was increased to 160 rooms at the \$ 109/night rate. When these were sold out, another 40 rooms were set aside for UOAA, but at the increased price of \$ 129./night. Once these are sold out, we will try to increase our block at the \$ 129.00/night rate ... but as there are fewer rooms in the hotel available, the Marriott becomes more resistant to price discounts. Their standard room rate is \$ 249.

If you plan to attend the Conference, and have not made your room reservation, please do it as soon as possible. If, after talking with the reservation people, you are told that there are positively no rooms available at the \$ 129.00/night price, please report this to Joan McGorry at 800-826-0826. Joan will take your contact information and will alert you to

the steps that UOAA has taken on your behalf.

There are two hotels within 15 minutes walking distance to "our" hotel. Both of these are also managed by Marriott ... one is a Courtyard, the other at SpringHill Suites. If we cannot negotiate an additional room block for the Lincolnshire Marriott, we will attempt to block rooms in the Courtyard. We recognize that it is better to have a sleeping room in the same hotel as the Conference and will take every step to try to make this happen, but we also recognize that the price of the room is an important issue for many.

### 2) **A NEW ADVOCACY SERVICE**

UOAA has entered into an agreement, effective July 1, 2007, with Jennifer Jaff, whose corporation, Advocacy for Patients with Chronic Illness, will provide the following information, advice and advocacy services **at no cost, to people who are members of UOAA's Affiliated Support Groups:**

- How to conduct health and disability insurance appeals;
- Guidance when applying for Social Security disability benefits;
- Assistance in obtaining workplace and school-based accommodations, and, when appropriate, representing people in negotiating conflict resolution with employers and schools;
- Assistance in locating needed health related services in the patient's geographic area;
- Addressing the needs of patients to the extent possible, including the identification of local attorneys if necessary.

- Court litigation is not part of the free service.
- UOAA will pay “Advocacy for Patients” a monthly fee for these services.

Jennifer Jaff, herself a Crohn’s Disease patient, who works from her office in Farmington, Connecticut, is admitted to practice law in Connecticut, New York State and the District of Columbia. Advocacy for Patients is a 501(c)(3) tax-exempt organization and does not charge patients for its services. Advocacy for Patients is funded by, among other sources, grants from foundations and companies that engage in health care-related advocacy, manufacturing, delivery and financing. Advocacy for Patients has an agreement similar to UOAA’s with CCFA.

People who want to use this “free” service should call Joan McGorry at our UOAA Administrative Office – 1-800-826-0826 and let her know of your interest. The contact information and brief reason for seeking this service that Joan gathers between now and June 30<sup>th</sup>, will be turned over to Jennifer on July 1<sup>st</sup>.

For the present, reimbursement issues will still be addressed by Linda Aukett, Chair, UOAA Advocacy Committee ... she can be reached at [advocacy@uoaa.org](mailto:advocacy@uoaa.org)

### 3) NEW IRS POLICY

Sheldon Sokol, UOAA’s Legal Advisor has brought to my attention the fact that the IRS has instituted a new filing requirement for small tax-exempt organizations ... a regulation that includes all of UOAA’s Affiliated Support Groups that have their own EIN or who claim to be tax-exempt.

- Beginning in 2008, small tax-exempt organizations, who previously were not required to file a return, may be required to file an annual electronic notice, Form 990-N, entitled “*Electronic Notice (e-Postcard) for Tax-Exempt Organizations not Required to file Form 990 or 990-EZ.*” This filing requirement applies to tax periods beginning after December 31, 2006
- The Pension Protection Act of 2006 requires small tax-exempt organizations

whose gross receipts are normally \$25,000 or less, and who are not required to file form 990 or 990-EZ, to now file **form 990-N**. This applies to all such groups, including the ASGs who are included in UOAA’s group return.

- The form will be filed electronically (via the Internet).
- The first filing deadline for the FY 2007 will be May 15<sup>th</sup>, 2008 (assuming your FY is on a calendar year basis, i.e. January 1<sup>st</sup> to December 31<sup>st</sup>.)
- Starting in July 2007, the IRS will start mailing “educational” letters to all organizations that may have to file this form starting in July 2007. If your group does not get a letter, it does not mean that you are exempt from filing ... it may simply mean that they do not have the current address of your organization. If you believe the IRS may have an incorrect address for your group, you need to file Form 8822, *Change of Address*, completing Parts II and III. You can get Form 8822 online at [www.irs.gov/eo](http://www.irs.gov/eo) and click on “Forms and Publications”. If applicable, you need to file Form 8822 now.
- Organizations that do not file the required form for three consecutive years will have their non-profit status revoked.
- The latest information about this filing can be obtained from the IRS website: [www.irs.gov/eo](http://www.irs.gov/eo) or by calling customer service at 1-877-829-5500.

### ❖ IN CONCLUSION

The UOAA Management Board of Directors believes that our agreement with Advocacy for Patients represents yet another service that UOAA can offer to the members of its affiliates. UOAA is more than just an organizational structure ... it is a provider of services that the affiliated groups could not provide on their own!

Best wishes for now,

*Ken Aukett*