



**UOAA UPDATES** are our way of communicating what is happening within UOAA to you, our members - and hopefully to your members too . We hope you are including some of the news in your newsletters or are 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 9, 2009

### □ ELECTION RESULTS

The only contested seats on the UOAA Management Board of Directors in this Fall's election were the 2 Directorships. The returns are now final and the two candidates that were elected are Susan Burns and Steve Strizic. I have spoken to the 3<sup>rd</sup> candidate, Harvey Shatz, and was advised by Harvey that he will continue to be active in UOAA and will undertake any assignments that President Kristin Knipp wishes him to undertake.

UOAA's Management Board of Directors effective January 1<sup>st</sup>, 2010 will be as follows:

- President, Kristin Knipp
- President-Elect, Dave Rudzin
- Vice President, LeeAnn Barcus
- Treasurer, Scott Bowling
- Secretary, Carol Haack
- Director, Susan Burns
- Director, Lynne Kramer
- Director, Bob Parish
- Director, Steve Strizic

I know that you join with me in wishing the new MBoD well with the knowledge that their deliberations will serve the very best interests of UOAA, its affiliated support groups and their members.

### □ IRS 990-N FILING REMINDER

All ASGs who have IRS charity status under the UOAA umbrella, or who have obtained IRS tax-exempt status on their own, must file information annually to the IRS. In most cases, all you need to file is a 990-N "e-Postcard," which can only be filed electronically, but is easily handled at <http://epostcard.form990.org>. Large groups with gross income over \$25,000 must file form 990 or 990-EZ instead of the 990-N.

In filing your group's 990-N or other IRS information return, it is essential to use your correct EIN (Employer Identification Number), not the EIN of

the UOAA national organization or of any other ASG. Joan McGorry is currently preparing letters to send to all ASGs under the UOAA umbrella. If you aren't sure of your EIN, please wait for this letter before filing. Also, if you are among the 29 ASGs submitted to the IRS this September, do not file until you receive Joan's letter to verify that you've been added successfully to the UOAA umbrella.

The 990-N or other IRS information return for each tax accounting year is due on the 15th of the fifth month after the tax year ends. For example, if your accounting year corresponds to the calendar year, your filing for tax year 2009 is due by May 15, 2010. All groups under the UOAA umbrella do, in fact, have an accounting year coinciding with the calendar year. Groups who've obtained exempt status on their own may have a different accounting year.

There is no penalty for filing late during a given year, or even for failing to file entirely during a particular year. However, if you don't file for three consecutive years, you'll lose your exempt status. Therefore, if you were required to file in 2008 and 2009, but didn't file during those years, you really need to file before the deadline in 2010.

Remember that this filing requirement applies only to ASGs under the UOAA umbrella and ASGs who've obtained exempt status on their own. It doesn't apply to hospital-run groups, whose IRS filing requirements would normally be handled at a higher level in the hospital organization. It also doesn't apply to ASGs who had exempt status under the old UOA umbrella but haven't come under the UOAA umbrella yet, since the old UOA umbrella isn't valid any more.

We are planning another IRS submission to add ASGs to the UOAA umbrella in March 2010. If your ASG would like to be included, please notify Joan at [oa@uoaa.org](mailto:oa@uoaa.org).

## □ **QUALITY OF LIFE WITH A PERMANENT ILEOSTOMY OR COLOSTOMY SURVEY**

Recently I received the following letter from Doctor AM El-Tawil, MRCS, MSc, PhD in the Department of Surgery at the University Hospital Birmingham in England

*“Dear Mr. Aukett,  
Creation of a permanent ileostomy is one of the surgical options available for managing cases with intractable constipation. We need to know the outcome of this procedure on the quality of life of patients. For this reason, we created a short, comprehensive questionnaire. I wonder whether it would be possible to distribute this questionnaire to your affiliated support groups and ask their leaders to invite their members to complete the questionnaire and e-mail it back to me.*

*Thank you for your assistance in undertaking this scientific endeavour.*

*Sincerely yours,*

*AM El-Tawil, MRCS, MSc, PhD  
[atawil20052003@yahoo.co.uk](mailto:atawil20052003@yahoo.co.uk) “*

## □ **LETTER TO DIRECTOR OF GRAY’S ANATOMY**

*November 14<sup>th</sup>, 2009*

*To: The Executive Producers of **Grey’s Anatomy**  
Shonda Rhimes, Betsy Beers, Mark Gordon, Rob Corn, Krista Vernoff, Mark Wilding  
The Prospect Studios  
ABC Television Center (West)  
4151 Prospect Ave  
Los Angeles, CA 90027*

*As a person with a colostomy, I would like to comment on the episode of **Grey’s Anatomy** that aired in Minneapolis, MN on Thursday Sept. 24<sup>th</sup>, 2009. Season 6, Episode 2. After managing Crohn’s Disease for over 40 years and having numerous bowel resections, I ended up with a permanent colostomy in 2003 due to surgeon error when she punctured my intestine. It was discovered too late before my kidneys starting shutting down and an emergency colostomy was performed to save my life.*

*I was frustrated, disappointed and alarmed during that episode, when confronted with surgery,*

*the patient, who has a bowel infection asks, “What is the worst possible thing that could happen to me?” And Cristina responds, “You’d end up with a colostomy bag.” The patient starts to cry and responds “No, no ... no poo bag for me! My Grand Dad had one of those! I won’t do it!”*

*Later on in the show, Cristina is reprimanded by Dr. Bailey. Dr. Bailey says “Well, thank you very much for threatening my patient with a colostomy and talking her out a life saving operation.” She retorts back, “What was I supposed to say? How am I supposed to sugar coat a colostomy?” Once again, words like “threatening” and “sugar coating a colostomy” makes having a colostomy a negative image. I do give you credit for the exchange of words further into the episode where Dr. Bailey says to Dr Yang, something to the effect of it was a fragile situation and the patient needed time to accept it.*

*This short conversation sparked my anger and the catalyst for this letter. The writers of the show obviously gave no thought what so ever to the thousands of people who have colostomies.*

*We are not all “old Grandpas” like depicted in the patient’s comment. We are mothers, spouses, children, young, old, sisters, brothers, co-workers and employers. We have survived colon cancer, Crohn’s disease, colitis, inflammatory bowel disease, bowel resections, anal cancer, ileitis, trauma and birth defects. It was disheartening to have the patient ask, “What the worst possible thing that could happen to me?” and to have the answer be “a colostomy”. The WORST thing that could happen is that the patient could have died. I sat in front of the TV thinking.....what about all the viewers out there that may be scheduled for an ostomy due to cancer or others that have suffered years of inflammatory bowel disease that have finally decided to have the surgery and then to hear that it “is the worst thing that could happen.”*

*I understand that Grey’s Anatomy is just a TV series. But as successful as it is, and the number of viewers it can have an impact on, I would have thought you would have taken the opportunity to have Cristina say, “A colostomy will save your life. It may take some*

*adjusting to, but you can have a long and healthy life with it.” But, instead, the writers portrayed it as something negative and undesirable. We, as ostomates are trying so hard to erase the stigma that goes with it and that episode certainly didn’t help. I’m sure you are aware, in real life, that ostomies have saved 1000's of people’s lives who are now leading productive, healthy and successful lives.*

*As a patient who endured a surgeon’s error and must live the rest of my life with a colostomy I would encourage your writers to think twice about what is written and to reflect whether anything in the script will have an impact on a certain group of people. After my surgery I turned my anger into being pro-active and being involved in something positive. I am a patient advocate and I speak not only for myself but for others about this episode. I do hope it will make a difference in how you write and how you view a colostomy....that it is NOT the worst thing that can happen to you! None of us really wanted one, but it became a necessity for some people who have had years of enduring pain and/or cancer. If a person had an artificial limb or a hearing aid, or a wheelchair other people would freely accept that, but when it comes to such a personal part of a person’s bodily function such as an ostomy, it is more difficult to accept and to talk about. I am trying to increase awareness of having a colostomy and not being ashamed of it. Your episode made me feel ashamed again. But it should really be the writers of **Grey’s Anatomy** that should feel ashamed of how you made some of your viewers feel.*

*Sincerely,*

*Darlene Hafner and the Minneapolis Chapter of the United Ostomy Associations of America.  
The ostomy group and I would appreciate and welcome any comments any of you might have.*

## □ **IN CONCLUSION**

Linda and I would like to convey our warmest wishes to you, your fellow support group leaders and your members, for a joyous Holiday Season ... and please be careful, with all of the kissing and hand shaking associated with this time of good will, remember the flu is lurking out there to attack you when you least expect it!

**KEN AND LINDA  
UOAA CO-FOUNDERS**