



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.

MARCH 1, 2008 COLON CANCER AWARENESS MONTH

UOAA IS NOW A CO-SPONSOR OF THE GREAT COMEBACKS® AWARD

On February 27th ConvaTec held its Great Comebacks® Award Dinner in Washington, D.C.'s Newseum, The Great Hall of News, a new museum that will open to the public this April.

The Great Comebacks® Program raises awareness of quality of life issues for people with Crohn's Disease, ulcerative Colitis, colorectal cancer and other diseases that can lead to ostomy surgery.

It was a special occasion for UOAA when ConvaTec President, Dave Johnson welcomed UOAA and IDEAS* as new co-sponsors of the Great Comebacks® Program, joining long-time Program sponsors, CCFA and ConvaTec. This marks the first time in the 23 years that the Great Comebacks® Program has been recognizing ostomates that have attained a laudable quality of life after ostomy surgery, that a national ostomy association will serve as a co-sponsor. I was given to opportunity to address the attendees and bring them up to speed regarding UOAA and its plans for the future. UOAA's logo will appear on all Program literature and publicity, and our President Elect, Kristin Knipp, has been invited to serve as a member of the Advisory Committee along with Rolf Benirschke, Al Geiberger, Marvin Bush, Dr. Victor Fazio and Suzanne Rosenthal, just to mention some of the other members.

At the Dinner, the four 2007 Regional recipients of the Award were recognized: Scott Ellis, Mike Florak, Wendy Lueder (President of the Broward County, Florida, Ostomy Association) and Jeffrey Larsen.

Scott Ellis, a firefighter from Enfield, Connecticut was selected as the National Award recipient. For more information visit: [Great Comebacks\(R\) Program Announces 2007 National Award Winner](http://www.prnewswire.com/cgi-bin/stories.pl?ACCT=104&STORY=/www/story/02-27-2008/0004764118&EDATE=) or: <http://www.prnewswire.com/cgi-bin/stories.pl?ACCT=104&STORY=/www/story/02-27-2008/0004764118&EDATE=>

Featured speaker at the Dinner was Rob Hill. Rob is the 34-year-old ileostomate mountain climber from British Columbia who took on the challenge to climb the tallest mountain on each of the seven continents. Having successfully climbed 6, he will leave for Nepal on March 22nd to start his quest to become the first ostomate and Crohn's patient to climb Mt. Everest.

Rob's motto is "**No guts, know glory**". His venture is being sponsored by ConvaTec. To follow his mission you are invited to visit www.greatcomebacks.com where daily blogs recording his activities will be posted. Rob Hill is the founder of the Intestinal Disease Education and Awareness Society (IDEAS*) that provides information to children about intestinal diseases.

For more information about IDEAS visit their website at <http://www.ideas-na.com>

ADVOCACY ... Direct from our meeting in D.C.

Ostomy management products are **prosthetics**! The 600,000 individuals with an ostomy in the United States are a special needs group within the general population. After surgery, we know that ostomates can remain active despite the loss of continence; however, no two patients manage their ostomy the same way. Suppliers provide patients post-surgery with medically necessary items that effectively replace the function of the bladder, colon and rectum. These include not only pouches, but also skin barriers, skin care treatments and accessories to ensure a secure fit for the patient.

We ostomates tend to refer to our stoma management products in generic terms such as "appliances" or "stoma bags" or just "pouches". Ostomy products are often inappropriately grouped with "medical supplies" for reimbursement by public and private payers. The items included in the "medical supplies" group include gauze pads, tongue depressors, cotton balls and band-aids, but most certainly should not include ostomy products. Ostomy products are "**prosthetic devices**" since

they replace all, or part of an internal body organ. Buried deep in the Social Security Act is the statement that **prosthetic devices** include colostomy bags and supplies related to colostomy care. Over the years this coverage has also been understood to apply to ileostomy and urostomy pouching systems.

Therefore, to keep this fact in front of our legislators, we have to start writing and talking about our **prosthetic devices** and not our bags or appliances. There may come a time in the near future when the powers-that-be may take the position, for example, that one type of pouching system is good for all people with ileostomies. We know that no two people manage their ostomy the same way ... that we need **prosthetic devices** that allow us to choose the system that works best for us. So in the future when referring to that “thing” attached to our abdomen, remember “appliance” ... bad; “**prosthetic device**” ... good!

ELECTION RESULTS

To those ASGs that exercised their right to vote, thank you! We again have a Secretary. Susan Burns was the successful candidate. Our thanks to the other candidates: Bob Parish and Michael Guss. Susan’s term commenced March 1st, 2008 and will continue through December 31st, 2009. Susan will continue participating as a member of the 2009 New Orleans Conference Planning Committee.

FALL, 2008, ELECTION

Again this Fall you will be asked to elect two Directors. Attached to this UPDATE are two documents prepared by our Chair of the Nominations and Elections Committee, Ginnie Kasten. The first contains information about the election process; the second is a nomination form.

CONSTITUTION AMENDMENTS THAT ARE ELECTION-RELATED

This January the ASGs approved the following amendments to the Constitution that will impact all future elections.

- Candidates for the UOAA Management Board of Directors shall be a member of a UOAA Affiliated Support Group, and their candidacy shall be endorsed by the leadership of their ASG.
- Candidates for the UOAA Management Board of Directors shall not be an employee of an ostomy product manufacturer or distributor.

ASG LEADERSHIP ADVISORY BOARD

Your MBoD has established an ASG Leadership Advisory Board that will serve as a non-voting, proactive resource through the provision of advice and counsel regarding UOAA’s activities. With this new Board in place it will ensure that UOAA’s management body is in tune with the needs and interests of the ASGs. It is hoped that this action will also stimulate grass-root level interest in UOAA’s management affairs.

The 4 ASG Leadership Award recipients will be invited to serve on the Advisor Board. In addition the MBoD will appoint 4 members. The terms of service will be 2 years. The 2007 Award recipients, Eileen Bohrer, Demi Cotrupe, Harvey Shatz and Mary Lou Thomas will make up the Board for 2008. The MBoD will appoint 4 more people, from nominations made by the ASGs, to serve commencing January 1, 2009. The Board will elect their own Chair. Contact Ken Aukett at kenaukett@uoaa.org for further details.

CWONurse ON CALL AT UOAA OFFICE

Joan McGorry advised the MBoD that telephone calls were coming in to the UOAA Office from people seeking personal ostomy management information on an increasing frequency basis. Joan, utilizing the WOCN Society Directory, has been referring these calls to an ostomy nurse in the caller’s geographic area; however, on many occasions there is not a nearby nurse.

To resolve this problem UOAA has entered into an agreement with Rita Hillis, a retired RN, BSN, CWONurse who lives in Frankewing, Tennessee, who will serve as **UOAA’s CWONurse on Call**. If Joan cannot identify a local ostomy nurse, then she will call Rita with contact information. Rita will communicate directly with the person seeking advice. UOAA views this action as a valuable service to the nation’s ostomy community.

SUPPORTIVE MEDICAL PROFESSIONAL

In another action aimed at recognizing those medical professionals that support the work of the ASGs, the MBoD approved the concept of a “Supportive Medical Professional”. Persons so identified will receive periodic information about UOAA activities, a one year subscription to **The Phoenix magazine**, a certificate of recognition, and will have their contact information listed on the UOAA website. The annual fee for this title is \$ 25.00

Do you have a WOC Nurse that is the backbone of your support group? Have you been looking for a way to say thank you? Are you aware that **April 13th to the 19th is WOC Nurse Week**? Why not honor that special person in your group by making them a **UOAA Supportive Medical Professional**? Contact Joan McGorry, oa@uoaa.org for an application form.

WOC NURSE OF THE YEAR AWARD

And here is yet another way to pay tribute to that outstanding WOC Nurse in your support group by putting their acts of professional dedication to your local ostomy community in the national spotlight!

UOAA is requesting its ASGs to submit nominees for the 2008 **WOC (ET) Nurse of the Year Award**. This Award will be presented to the recipient in the presence of their peers at the WOCN Society's National Conference, Conference, convened from June 21st to the 25th in Orlando, Florida.

Nominees must be a member of your support group, attend your meetings, and must have presented an educational program to the support group within the past year.

Applications must be received by April 30th, 2008. Submit the form to Jan Clark, Selection Committee Chair, by e-mail: janclark@sbcglobal.net; by mail to Jan Clark at 943 W. Woodlawn Avenue, San Antonio, TX 78201; or by FAX at 210-734-8274. Contact Jan Clark for nomination form.

MID WEST ASG LEADERSHIP SEMINAR

Time is getting short to register for the ASG Leadership Seminar that will be held on Friday evening, **April 4th and Saturday, April 5th** at the Holiday Inn Select, in **St. Peters, Missouri** just outside of St. Louis. See the attached flyer for details. Remember **each ASG** that sends a representative is entitled to an expense rebate from UOAA of \$ 100.

Please contact LeeAnn Barcus at LeeAnn@uoaa.org if you plan to be there. We have much to discuss and need you input!

SOUTHEASTERN REGIONAL SEMINAR HOSTED BY THE PALM BEACH OSTOMY ASSOCIATION

UOAA's first 2008 Regional Conference will be hosted by the **Palm Beach Ostomy Association**

and held on **Sunday, March 30, 2008**, at the JFK Hospital, 5301 South Congress Avenue, Atlantic, Florida. Proceedings will begin at 9:00 am and continue until 5:00 pm. A continental breakfast and luncheon will be served.

There will be no registration fee.

This Seminar will feature presentations by the President of UOAA, the Past President of the WOCN Society and the Past President of FOW-USA; interactive round table discussions; an ostomy product exhibition; and, a free Stoma Clinic where you will have a one-on-one meeting with a WOC Nurse.

Additional information about this Seminar can be obtained by contacting **Dick Norman** by telephone at **561-784-4496** or by e-mail at n1464@att.net

GYGIG 2008 RIDE SCHEDULE

With Spring right around the corner, dust off and oil up your bicycles ... its time to Get Your Guts in Gear!. The schedule for 2008 is:

- In the **New York** Area on June 6th to the 8th
- **Seattle**, WA Area, August 1st to the 3rd
- In the **Austin**, TX Area, October 17th to the 19th



IN CONCLUSION

I hope that you share my enthusiasm for the good things that are happening to UOAA. Word of UOAA and its Affiliated Support Groups will be linked to The Great Comebacks® Program, we have instituted an ASG Advisory Board, provided a way to recognize Supportive Medical Professionals and increased the services we provide from our administrative office ... and its just March. Just think what the rest of the year will bring!

While in Washington I saw my first flock of robins this year, and the spring bulbs are pushing their way through the soggy earth in my backyard. Looks like we made it through another winter ... at least here in New Jersey!

With very best wishes for now,

Ken Aukett - President, UOAA