



*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 2006**

## **UPDATES:**

### ❖ **Fall 2006 Election of UOAA Management Board of Directors.**

In order to get UOAA off and running, last year this time a Management Steering Committee of select individuals was assembled. This committee was charged with developing an organizational mission statement, writing a constitution, implementing policies and procedures, gaining corporate non-profit and IRS charity status, raising operating funds, entering into contracts for the publication of a quarterly magazine, The Phoenix, and for an Office Administrator, selecting a webmaster to establish a comprehensive website, meeting with industry representatives to gain their support, interacting with WOCN, CCFA, ACS and other kindred agencies to begin working relationships, and, possible the top undertaking, reaching out to the nation's ostomy support groups to encourage them to affiliate with us. Those entrusted with these tasks included Julielyn Gibbons as Vice President, Ginnie Kasten as Secretary, Dave Rudzin as Treasurer, Charlie Grotevant and Ron Titlebaum as Directors and myself as President.

As promised, an election will be held this Fall for the Affiliated Support Groups to determine who will guide the fate of UOAA through 2009. At this time you are being asked to nominate candidates to take on National leadership roles. Later this year you will be asked choose which of these candidates will best serve UOAA. Remember that the number of votes an ASG can cast coincides with the number of members for which they will pay an annual affiliation fee. One member .. one vote. Those ASGs that have reported "no members" will have 12 votes.

Attached to this UPDATE are two documents written by Ginnie Kasten as Chair of the Nominations and Elections Committee. The first entitled UOAA Election Blurb describes the election process. The second document, Prospect Fact Sheet and Agreement to Serve Form will be used by you to nominate candidates.

In addition to Ginnie Kasten, the Nominations and Elections Committee that will conduct this election,

consists of Mary Beth Akers, Stanley Cooper, Kathy DiPonio, Kellie Stritman and Steve Strizic.

### ❖ **Membership Verification**

You have recently received a message from our Office Administrator, Joan McGorry asking you to verify the number of members that are in your support group. If you haven't received this email please contact Joan at 800-826-0826. In some cases this number will differ from the number you reported when you affiliated with UOAA. This number will be used to: 1) determine the number of votes you will have in the upcoming election; and, 2) serve as the basis for your Annual Affiliation Fee. The fee rate for 2007 will be \$ 2.00/member, so, for example, if you report that your ASG has 25 members, your Annual Affiliation Fee (AAF) due January 1<sup>st</sup>, 2007 will be \$ 50. Those ASGs that report "no members" will have to pay an AAF of \$ 25.00 and will have 12 votes in the election.

### ❖ **Remember ... UOAA Contact Information**

UOAA's "contact address" is now:

**UOAA**

**P.O. Box 66**

**Fairview, Tennessee 37062**

and Joan McGorry can be reached by telephone at:

**800-826-0826 (the UOAA Help Line)**

or by e-mail at [oa@uoaa.org](mailto:oa@uoaa.org)

### ❖ **Visiting Program Support**

One of the most important services that an ASG has is its "Visiting Program". This service is viewed as being so important that UOAA requires that a support group has an active Visiting Program before its affiliation application is accepted.

In order to enhance this service UOAA has activated an e-mail visiting service contact address at:

[ostomy\\_visitor@uoaa.org](mailto:ostomy_visitor@uoaa.org)

People looking for a "visitor" can e-mail their request to this address. Joan will then forward these messages to the ASG geographically closest to the requestor. UOAA will publicize this e-mail address in *The Phoenix* and on the UOAA web site.

### ❖ **Articles for Newsletter**

As a service to ASG Newsletter Editors, UOAA will include, with each UOAA UPDATE, a group of

articles that can be used by Newsletter Editors as educational material for their newsletter. When the next group of articles are distributed with the next UOAA UPDATE later this summer, this group will be placed on the UOAA website. By doing this Newsletter Editors will have first crack at the material, and then the articles will become part of a **library** open for all website viewers to read.

❖ **WOCN Conference**

On June 25<sup>th</sup> through the 27<sup>th</sup>, UOAA set up an exhibit booth at WOCN's 38<sup>th</sup> Annual Conference held in Minneapolis, MN. Thanks to the belief in UOAA by a one-time ostomy Chapter President, now President of WOCN, Margaret Goldberg, UOAA's booth was complimentary. Since one of the educational workshops "summarized the creative methods of meeting the ongoing needs of the ostomy patient **in the absence of UOA**, it was most important for the attendees to know that UOAA does exist, that the local support groups are alive and well and that services to their patients are equal to, or better than those of the past! Handout packets included an up-to-the-date listing of the Affiliated ASGs with contact information together with other UOAA organizational material.

Booth staffers included Joan and myself pushing UOAA, Kristin Knipp talking about the YODAA Conference in Cleveland this August, and Linda providing information about the Youth Rally. The shining star of our exhibitor team, however, was Eileen Bohrer of the St. Paul Ostomy Association. Eileen took charge of printing, assembling and stuffing our 1,000 handout packets, assisting with the booth setup and take down. By engaging passers-by in conversation and physically steering them into our booth, Eileen guaranteed that they got the message. Her friendly, smiling "strong armed" method was most effective!

Also included in the packets were 10,000 subscription cards for **The Phoenix** that the nurses were asked to pass out to their new patients.

❖ **Get Your Guts In Gear Rides – "GYGIG" – New York Ride**

There was an early morning mist on Pier 54 that extended out into the Hudson River. As a representative of UOAA, one of the beneficiaries of the GYGIG 2006 Rides, I was invited to give the 78 assembled cyclists a few motivating words of encouragement as they took off on a three day, 217 mile venture from Pier 54 to the campus of Skidmore College in Saratoga Springs, NY. The weather enroute was cooler than last year, but the winds were a challenge, and the thunderstorms at night raised havoc with the pup tents in which they were bedded down. On Sunday afternoon I had the

pleasure of welcoming the riders back to the world of soft beds and hot showers.

UOAA riders included, for the 2<sup>nd</sup>, and he says his last, year in a row, George Salamy; Bob Baker, President of the Greater Waterbury (CT) Ostomy Association, and Paul Heller, a New York anesthesiologist.

The ride is designed to promote awareness about IBD and related issues such as ostomy surgery, and to raise funds for IBD research projects and for patient support organizations.

A second ride, August 18-20, will take place in the Pacific Northwest with the riders making a 210 mile loop on scenic Whidbey Island and Washington's Skagit Valley. UOAA representatives, for this, GYGIG's first west coast ride, will be Charlie Grotevant, Julielyn Gibbons, Brenda Elsagher and Emily Mallar. Each participant in the ride has a fund raising goal he or she must meet. If you wish to support the UOAA riders there is still time for you to make a pledge on line at the GYGIG website, [www.ibdride.org](http://www.ibdride.org) - click on "donations". The pertinent rider numbers are:

Emily Mallar: S-14                      Brenda Elsagher: S-20  
Charlie Grotevant: S-30                Julielyn Gibbons: S-43

I would be remiss if I did not acknowledge the truly outstanding job Judy Pacitti, the Executive Director of GYGIG Inc. is doing in making this happen. Next year will be even more challenging for Judy as a third ride in Texas is added to the NY and WA rides.

❖ **Network News ... 30+ maybe another for 55+**

The governing committee of the 30+ network is discussing the advisability of putting a cap on the age limit for the 30+ Network at 55 years. If this happens, it will be their recommendation that a 55+ Network be established. If you have any thoughts on this matter I am sure that they would be welcomed by Steve Strizic, Network Chair. Steve can be reached at [sstriz@nventure.com](mailto:sstriz@nventure.com)

❖ **Affiliated Support Groups** – The groups that have affiliated with UOAA now number **205**.

You can see the entire list at this link:

<http://www.uoaa.org/supportgroups.shtml>

**Reminder:** In order to refer people to your group we need to keep the information on this list current.

Please remember to let us know if and when your contact person, telephone number and/or e-mail address changes. **Send changes to Joan McGorry at [oa@uoaa.org](mailto:oa@uoaa.org) . Thanks!**

❖ **YODAA Conference**

It's happening soon!! On August 2 – 6, 2006

**YODAA ROCKS CLEVELAND**

The Young Ostomate & Diversion Alliance of America Network will hold a **Young Adult National Conference** at the Hilton Garden Inn Cleveland Downtown. Hotel reservations can be obtained at [www.hiltongardeninn.com](http://www.hiltongardeninn.com) (use conference code – UOAA). Located in the heart of downtown Cleveland, the hotel is just minutes from the Rock N Roll Hall of Fame, the Flats and Warehouse entertainment districts. Visit UOAA's website [www.uoaa.org](http://www.uoaa.org) On the home page under "calendar" click on Young Adult Conference for links to the registration form and hotel reservations. Contact Kristin Knipp, Conference Chair, at [yodaa@uoaa.org](mailto:yodaa@uoaa.org) for help in finding a roommate.

In addition to many varied educational workshops, exhibit hall, special medical one on one sessions, opening night reception and closing banquet the conference will feature an appearance by fellow ostomate **JODI WEATHERTON of MTV's Real World/Road Rules Challenge: Gauntlet II**

**YODAA ROCKS CLEVELAND - BE THERE**

- ❖ **The Phoenix.** – A second subscription invitation was sent in June to all former UOA members who had not signed up for **The Phoenix**. Many people did not realize that the first copy of **The Phoenix** that they received was a complimentary issue and did not realize that they had to "subscribe" to get future issues. The Publisher, Ian Settlemire has recently sent each ASG the draft of a full page, ½ page and a ¼ page advertisement that can be placed in your newsletter. Since the revenue gained from these subscriptions is the primary source of UOAA funding, the more people that sign up for this educational journal, the more financially sound UOAA will become.

If you, or your members, wish to make any comments to Ian Settlemire, **The Phoenix** Publisher, they may be e-mailed to him at:

[publisher@uoaa.org](mailto:publisher@uoaa.org).

- ❖ **Website - [www.uoaa.org](http://www.uoaa.org)** Our website now contains a section dedicated to the provision of "Basic information about ostomy". This will help both old and new ostomates understand more fully the terminology for their condition and that of other ostomates.

**Does your group have a website?** UOAA is prepared to offer you space on its site where you can post contact and, any generic meeting information you wish for your group. This will be a no-frills page, but it will provide information about your existence to folks surfing the web. It will also

give you an Internet address that you can include on your brochure, business cards or newsletter. For more information contact Joan McGorry [oa@uoaa.org](mailto:oa@uoaa.org).

❖ **Upcoming Meetings**

UOAA will be represented at the **UOACanada** meeting that will be held on August 16<sup>th</sup> through the 20<sup>th</sup> in Moncton, New Brunswick, Canada at the Delta Beausejour Hotel.

UOAA will bring greetings to the Board of Directors of the Quality Life Association (QLA) when they meet in St. Petersburg, Florida on September 7<sup>th</sup>, 2006

UOAA will observe the proceedings of the IOA Executive Council when they meet in Orlando, Florida at the Ramada Inn on September 8-10, 2006

Ken and Linda Aukett have been invited to address the 2006 Guangzhou International Symposium on Stoma Therapy and Rehabilitation when it convenes in Guangzhou, China, October 6 to 8, 2006

The UOAA Management Board of Directors and 2007 Conference Planners will meet at the Lincolnshire Marriott Resort on November 9<sup>th</sup> through the 11<sup>th</sup>. ASG leaders in the Chicago area will be invited to participate in the conference planning discussions on Saturday, November 11<sup>th</sup>.

**FUTURE PLANS:**

❖ **World Ostomy Day – October 7<sup>th</sup>, 2006**

Observance of this event provides an excellent opportunity to generate public awareness about ostomy surgery, the diseases that result in ostomy surgery and the local support groups that are organized to assist ostomy patients, their families and caregivers. Attached is a letter from Joan McGorry, UOAA WOD'06 Coordinator with some planning ideas.



- ❖ **Inaugural UOAA National Conference – Thursday, August 16<sup>th</sup> through Saturday, August 18<sup>th</sup>, 2007**, Its not too early to start planning to attend this historical event. Check the [www.uoaa.org](http://www.uoaa.org) website for details.

- ❖ **IN CONCLUSION ... THAT JUST ABOUT SUMS UP THE NEWS FOR TODAY. STAY WELL, DRINK PLENTY OF WATER AND HAVE A GREAT SUMMER!**

*Ken Aukett, President, UOAA*