



Thanks to your encouragement and support, UOAA's foundations are firm and it has established itself as a viable organization, a worthy successor to UOA.

The following report is a summary of the activities taken by UOAA's Management Board of Directors, a look at events planned for the future and an overview of some of the items that will be of interest to your support group.

We continue to look forward to working with you and to being an active resource to ensure your success.

May, 2006

UPDATES:

- ❖ **UOAA Contact Support Office.** I am pleased to announce that UOAA now has an official home and someone to manage it. Effective April 1st, 2006, UOAA signed a contractual agreement with **Joan McGorry** who will serve as our **Office Administrator**. Joan will work from her home in Fairview, Tennessee. UOAA's "contact address" is now:

UOAA
P.O. Box 66
Fairview, Tennessee 37062
Joan can be reached by telephone at:
800-826-0826 (the UOAA Help Line)
or by e-mail at oa@uoaa.org

For those not familiar with Tennessee, you will find Fairview on the map, about a 45-minute drive south and west of Nashville.

To Joan, the word "ostomy" has been in her vocabulary for many years.

An ostomate herself, she now has a standard ileostomy, having lived with a J-pouch for a number of years. Before moving from the Minneapolis/St. Paul area, Joan was active in the St. Paul ostomy support group and continues to serve as the volunteer editor of their newsletter. If you have trouble identifying Joan's accent, the fact that she lived on Long Island, New York may be the confusing factor.

Joan brings an impressive background of both corporate and private management experience to her UOAA Office Administrator's position and will be most helpful to the UOAA's Management Board of Directors in defining the full scope and responsibilities of this position. One of her key duties will be answering the toll free "help line", 800-826-0826, that has been averaging close to 350 calls per month since last October.

- ❖ **IRS Application for 501(c)(3) Status**
I was quite happy to learn that the letter I received from the IRS, on April Fools Day, April 1st, was not a joke, but actually notification that our application for **501(c)(3) "charity" status** was approved. This will allow anyone making a contribution to UOAA or to an ASG that has requested coverage

under UOAA's charity umbrella, to deduct the gift from their Federal Income Tax. The IRS approved our application on March 22nd. The approval applies to all contributions made to UOAA since August 15th, 2005.

Joan has already sent ASGs a notice about this, but if your ASG wants to be covered under UOAA's IRS 501(c)(3) umbrella there is a protocol that must be followed:

- 1) **A letter must be sent to the UOAA OA (e-mail works) advising us that your group wants this coverage;**
- 2) In this letter you must reaffirm that your bylaws/constitution contains a clause that, upon dissolution of your group, any remaining assets will be distributed to other 501(c)(3) organizations, and not to individual ASG members;
- 3) **You must have a Federal EIN** (Employer Identification Number). This number is like your Social Security Number ... it identifies who the group is. You cannot use UOAA's EIN!

Note: If your ASG does not have an EIN, it can be obtained quite simply by calling the IRS at **800-829-4933** from 7:00 am to 10:00 pm. Before making this call it is suggested that you complete IRS form SS-4 for reference purposes... download [form](#) and [instructions](#). If you are now applying for your EIN, please e-mail Joan immediately at oa@uoaa.org once you receive your number. The process is really easy ... it took me less than 10 minutes to get an EIN!
- 4) UOAA has to make an application to the IRS listing those AGSs that are included under its 501(c)(3) umbrella. This application will be made on, or about **May 24th**. The application consists of over 50 pages and there is a \$ 500 IRS processing fee associated with it, so if you miss the May submission date, the next submission may not occur until the August/September 2006 timeframe.

- ❖ **Affiliated Support Groups** – The groups that have affiliated with UOAA now number **187**, which includes groups in Bermuda and Puerto Rico - we are international! 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 . Thanks!

In the past UOA had Chapters and Satellites. Today, UOAA has Affiliated Support Groups and (to adopt the term introduced to us by the Staten Island Ostomy Association) “**Outreach Support Groups**” or “**OSGs**”. If your ASG has an Outreach Support Group that you want listed in the UOAA Directory, please send contact information (OSG name, contact name, postal address, tel/fax and e-mail address) to Joan McGorry. Your OSG will be listed under your listing in the Directory. Note that you will be responsible for keeping your OSG information current. OSGs will pay no affiliation fee since their membership is included in your membership total. Likewise their votes on UOAA affairs will be cast by you as the parent ASG.

- ❖ **The Phoenix.** As an encouragement for support group members to subscribe to **The Phoenix**, UOAA is offering a special incentive to ASG members only: **the 20/20 Program**. 20 members of your group can get a one-year subscription for only \$ 20.00 each. This offer is extended only to members who are not currently subscribers to **The Phoenix**. Send a listing of their names and addresses to **The Phoenix** Publisher, P.O. Box 3605, Mission Viejo, CA 92690 together with a check for \$ 400. If you want to send more than 20 names, that is great, but obviously the check you send will reflect the \$ 20 per subscription amount. This is a one-year offer. When the subscriptions expire (after 4 issues) renewals will be at the then-current subscription price. Note the **free trial offer** for one copy is still in effect. Anyone can send their name and address together with a check for \$ 3.95 to cover postage and handling, to **The Phoenix** Publisher at the above listed address.

UOAA wishes to acknowledge Hollister’s belief that **The Phoenix** magazine is a valuable educational resource to all bowel and urinary diversion patients. To exhibit this belief Hollister is including a subscription card to the magazine in all of their “Secure Start” kits, the kits that patients receive upon discharge from a hospital and for a period of time thereafter.

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 .

- ❖ **Website - www.uoaa.org** Have you visited our site lately? We thank our advertisers that are supporting us, and our Webmaster, Bob Baumel, for the excellent job he is doing in maintaining a most professional site. We now have **four discussion boards**: General Ostomy Discussion; Continent Diversion; Teen Network; and Young Adults/YODAA. All together there have been a total of 12,908 postings since the boards opened last October. That represents a lot of shared information, empathy and compassion.

Does your group have a website? UOAA is prepared to offer you space on its site where you can post contact and generic meeting information for your group. This would 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 .

- ❖ **Advocacy** **UOAA wishes to acknowledge ConvaTec’s** outstanding support of its Advocacy Program. UOAA has received grants from ConvaTec that will fund the annual fees associated with website programs and other activities. Linda Aukett, Advocacy Program Chair, advises that very soon our public policy and communication program will extend to all 50 State legislatures, their laws and officials as well as Congress and the Federal system. This will help us to more effectively harness the voices of the bowel and urinary diversion community and their supporters, thereby enabling them to impact public policy. It will provide visitors to the www.uoaa.org website the opportunity to: view information about issues that affect them; see suggested messages that would inform public policy makers about these issues; identify their own public policy makers who need informing; and send the messages to them.

Use of this program will significantly assist UOAA in the attainment of its advocacy goals: to improve Medicare reimbursement of ostomy-related products; to campaign for the elimination of ostomy supplies from the bundled home health payment; to campaign for the exemption of ostomy supplies from National Competitive Bidding; to educate Congress about the value of increased funding for medical research; and, to educate UOAA website visitors about issues affecting them and to help them locate resources pertaining to other advocacy-related aspects of their lives such as discrimination, ADA, insurance and other items.

The internal program LegAlert will allow the Advocacy Committee to: conduct key-word searches, on the Federal and State levels, for proposed legislative actions that will impact on UOAA's issues; be alerted to recently introduced bills; access the full text of bills, amendments, hearing reports; monitor the scheduling of pertinent committee hearings and access committee reports; receive daily reports on watched legislation and other activity.

Advocacy is one of the cornerstones of UOAA's mission ... a service that, to be effective, requires the ASGs to be united. The more ASGs that affiliate with UOAA, the louder our voice, the stronger our combined clout!

❖ **WOCN Conference**

Thanks to the belief in UOAA by a one-time ostomy Chapter President, now President of WOCN, Margaret Goldberg, UOAA will have a complimentary exhibit booth at this year's WOCN Conference, to be held June 25th through the 27th in Minneapolis.

UOAA will be distributing information packets that will contain *The Phoenix* subscription cards and a support group affiliation form. There are currently 5 WOC Nurse-sponsored support groups affiliated with UOAA, and we hope to identify and affiliate many more. Knowing that these groups exist will be most helpful when inquiries come from new patients concerning the services that are available in their local area.

❖ **UOAA Meetings**

Strategic Planning Meeting - The UOAA Management Board of Directors met in the Libertyville, Illinois office complex of Hollister Incorporated on March 17 – 19 to engage in strategic planning and other UOAA related business. UOAA acknowledges and thanks Hollister Incorporated for providing a grant to support this activity.

Annual Meeting – UOAA Inc. held its first Annual Meeting in conjunction with the Mt. Laurel, New Jersey Regional Conference of April 21st, 2006.

❖ **UOAA Sponsored Conference Events**

On April 21-23 the ostomy support groups that comprise the **Delaware Valley Regional Taskforce** convened a Regional Conference at the Wyndham Hotel in Mt. Laurel, New Jersey. Over 150 attendees heard the keynote address presented by Barbara Barrie, author of "Don't Die of Embarrassment", and noted stage and TV actress, who shared her experiences with colon cancer and a colostomy. Other Conference highlights included a reception Friday evening, 10 industry exhibits and numerous

educational sessions on Saturday, and on Sunday workshops were held for both visitor training and for ASG leaders and volunteers to share their experiences and successes.

Harvey Shatz, DVRT Chairman, expressed his thanks to Hollister for sponsorship of the Saturday luncheon, Sterling Medical for the Sunday luncheon and ConvaTec for providing a grant for the two workshops on Sunday morning and a copy of Barbara Barrie's book to all attendees. A special thank you was extended to all of the WOC Nurses that assisted with the Stoma Clinic at which over 30 attendees received sound professional advice about their situation.

YODAA - On August 2 to 5, 2006 the Young Ostomate & Diversion Alliance of America will hold a **Young Adult National Conference** at the Hilton Garden Inn, in Cleveland, Ohio. For more details about this event contact Kristin Knip, Conference Chair, at yodaa@uoaa.org or visit UOAA's website www.uoaa.org and on the home page under "calendar" click on Young Adult Conference for links to the registration form and hotel reservations.

ASG SPOTLIGHT:

- ❖ Three of UOAA's ASGs celebrated significant anniversaries this spring. Congratulations to the **Ostomy Association of the Houston Area** and to the **Ostomy Association of Greater Springfield, Massachusetts** for **50 years** of compassionate help, and to the **Joplin Ostomy Association**, which had two charter members present to help them celebrate **35 years** of caring in southwest Missouri.

FUTURE PLANS:

❖ **UOAA Election**

UOAA will conduct **its first election of Officers and Directors this Fall**. On July 1st, give or take a few days, Ginnie Kasten, Chair of the Nominations and Elections Committee, will officially notify the ASGs of the election and will request nominations for Office and Director candidates. A President, President-Elect, Vice President, Secretary, Treasurer and 4 Directors will be elected, who will take office on January 1st, 2007. Each support group that has affiliated with UOAA prior to September 1st, 2006, will be eligible to vote in this election. **Each ASG will have as many votes as they declared were members of their group when they affiliated** ... one member, one vote. Those groups that reported "no members" will have 12 votes. On, or about October 1st, the N&E Committee will e-mail a ballot to each ASG. Ballots will be completed and e-mailed back to the UOAA OA by November 15th. The N&E Committee will tally the ballots and the results will be made

known by December 2nd. Now is the time to start thinking about who you would like to see in office ... maybe there is someone in your ASG that could assume a national leadership role .. maybe that someone is **YOU!**

❖ **Get Your Guts In Gear Rides – “GYGIG”**

As UOA benefited financially last year, UOAA will be a beneficiary of the two rides GYGIG is planning this year. These events, designed to put the spotlight on inflammatory bowel diseases and to raise awareness about the support that is available to IBD patients, feature 3-day, 200+ mile bike rides by hopefully 100+ riders. The first ride will take place on June 9-11 and will see the riders leaving New York City on Friday morning and arriving in Saratoga Springs Sunday afternoon. The second ride, August 18-20, GYGIG's first time on the west coast, will take place in the Pacific Northwest with the riders making a 210 mile loop on scenic Whidbey Island and Washington's Skagit Valley.

George Salamy will again be riding in the East Coast event, joined by Bob Baker, President of the Greater Waterbury Area Ostomy Support Group. UOAA representatives Charlie Grotevant, Julielyn Gibbons, Brenda Elsagher and Emily Mallar will ride on the West Coast. Each participant in the ride has a fund raising goal he or she must meet. If you wish to support the UOAA riders you can make a pledge on line at the GYGIG website, www.ibdride.org - click on “donations”. The pertinent rider numbers are:
Bob Baker: NY-11 George Salamy: NY-71
Emily Mallar: S-14 Brenda Elsagher: S-20
Charlie Grotevant: S-30 Julielyn Gibbons: S-43

❖ **World Ostomy Day – October 7th, 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.

You will be hearing more about WOD shortly from UOAA's National WOD'06 Coordinator, Joan McGorry.



❖ **Inaugural UOAA National Conference – Thursday, August 16th through Saturday, August 18th, 2007**

UOAA will convene its first National Conference at the Lincolnshire Marriott Resort, situated 18 miles northeast of Chicago's O'Hare airport. The hotel is located on a 170- acre site that features a golf course, in-door and out-door swimming pools, a health club, in-door racquet center, basketball and sand volleyball courts, bike rentals and bike paths that could take you to Wisconsin, and a playground for the kids.

The 3-story hotel has 384 well-equipped rooms featuring all of the Marriott amenities (20 of which are wheel chair accessible), wireless Internet in all of the public space, a Kings Wharf themed restaurant, a sports bar, and an award-winning live musical theatre-in-the-round, featuring the best of Broadway.

The room rate is only \$ 109 s/d ... compare this with the cost of downtown hotels that start at \$170. After a 10-minute cab ride and a 45-minute commuter train ride, you will be in downtown Chicago with \$ 61 in your pocket!

Kristin Knipp has been appointed as UOAA Conference Planning Chair.

PS: ConvaTec has promised to carry on its tradition of a sponsored themed social evening.

WE FONDLY REMEMBER:

With the death of **Florence Cohen** on February 15, 2006, the ostomy community lost a national and international treasure. She will be remembered fondly by all whose lives have been touched, both directly and indirectly, by this sensitive, loving woman from Boston. As a pioneer visiting program role model in the 1950's she was outstanding ... *“Look at me – I made it, so can you!”* .. encouragement personified.

Over the years Florence's accomplishments have been significant. She was an intellectual presence in the establishment of the Ostomy Association of Boston, the United Ostomy Association, and the International Ostomy Association, and was a strong supporter of the United Ostomy Associations of America. Florence saw the need and value of holding workshops at UOA Annual Conferences for ostomates with handicaps, for single ostomates by helping to organize the first “Singles Day”, and for other special interest groups such as the gay and lesbian ostomates. A compassionate woman, a true humanitarian, Florence Cohen dedicated her life to the provision of mutual aid and support to all people who have experienced ostomy surgery.

❖ **In conclusion**, I want to thank the ostomy product manufacturers and distributors who have been most supportive of our fledgling events and activities. They know that the post- surgery rehabilitation period can be most difficult if you are going it alone. The Ostomy Support Groups were organized to dispel the “I'm one in a million” syndrome. UOAA was organized to assist the Support Groups to accomplish their humanitarian mission. Industry is helping us accomplish ours!

Any comments you wish to share about UOAA, its programs and activities, or this UPDATE, please communicate with me at kenaukett@uoaa.org

Take care ... and thank you for caring!!

Ken Aukett
President, UOAA Steering Committee