



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.

November 2006

## UPDATES:

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

The balloting is completed and all that remains is for the Nominations and Elections Committee to tally the votes and announce the successful candidates. You can expect an e-mail from Ginnie Kasten, the N&E Committee Chair advising you of the results the first week in December.

To those successful candidates we extend our congratulations ... but to those who were not elected our sincere thanks. Thank you for stepping forward and announcing that you are interested being part of the team that is working to ensure that UOAA successfully attains its stated mission and goals. UOAA is dependent upon volunteers to develop and implement its activities and programs. It needs new faces with new ideas and talents to resolve the many issues facing UOAA and its affiliated support groups. Be assured that candidates who were not elected to the Management Board will not be put on the shelf, but will be utilized by the new administration. Our next election will be in the Fall of 2007 when 2 of our 4 Directors stand for re-election. It is not too early to encourage qualified people in your group to toss their hat into the ring. Their insights into UOAA issues will be appreciated.

A little over half of the ASGs voted in this election. In an effort to improve our election process, each ASG will receive, in the next few weeks, an "exit poll" from Joan McGorry. The purpose of this questionnaire will be to see what you thought went right and what went wrong with the election process we used, how the balloting can be simplified, and to learn why those ASGs that did not vote chose not to return their ballots. Hopefully we will gain information that will cause the number of ASGs casting a ballot in the 2007 to increase.

### ❖ Affiliated Support Groups – Since our last UPDATE in October, 7 more groups have affiliated. If you add in the 15 Outreach Support Groups (OSGs, formerly known as Satellites) associated with the ASGs, UOAA now represents **243 ostomy patient support groups!**

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 let us know if your contact person, telephone number and/or e-mail address changes.

**Send changes to Joan McGorry at:  
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](mailto:oa@uoaa.org)

Requests for visitors received on [ostomyvisitor@uoaa.org](mailto:ostomyvisitor@uoaa.org) will be forwarded by Joan to the nearest ASG.

### ❖ Annual Affiliation Dues (AAD)

In the next several weeks you will be receiving a notice from our office advising that your dues for your support group's affiliation with UOAA are dues. The dues are based on the number of members that you reported to UOAA when you affiliated, times the dues rate of \$ 2.00 per member set by the MBoD. As an example, if you reported that there were 30 members in your group, your AAD will be \$ 60. This is payable to UOAA on January 1<sup>st</sup>. If you reported "no members", then your AAD will be a flat rate of \$ 25.

Around July 1, 2007, you will be asked to tell us your current membership. This number will be used to determine the AAD payable January 1<sup>st</sup>, 2008. At the same time you will be told what the dues rate will be for 2008 so that you can budget accordingly.

### ❖ National Colorectal Cancer Round Table

I am pleased to announce that, following in UOA's footsteps, UOAA was accepted as a member of this prestigious organization. Jo Ellen Deluca from South Carolina will represent UOAA

The National Colorectal Cancer Roundtable (NCCRT) organized in 1997 by the American Cancer Society and the Centers for Disease Control and Prevention, is a national coalition of public, private, and voluntary organizations whose mission is to advance colorectal cancer control efforts by improving communication, coordination, and collaboration among health agencies, medical-professional organizations, and the public. The ultimate goal of the roundtable is to increase the use of proven colorectal cancer screening tests among the entire population for whom screening is appropriate. More information about NCCRT may be found on their website at [www.nccrt.org](http://www.nccrt.org)

## ❖ GYGIG Ride

Now here is some really good news! Judy Pacitti, the "Get Your Guts In Gear" Ride Director, attended our MBoD meeting in Chicago to discuss UOAA's involvement in the rides scheduled for 2007. As a beneficiary of the fund raising rides held in New York this past June and in the Seattle area last August, UOAA received, not only the benefits of a "ton" of great publicity about "ostomy", the diseases that necessitate ostomy surgery, the support groups organized to assist ostomates, and the fact that there is "nothing an ostomate can't do", but Judy was most pleased to present us with a check for our portion of the funds that were raised: **\$ 47,167 ... wow!**



From  
Left:  
Charlie  
Julielyn  
Edwin  
Judy  
Ken  
Bob

We are certainly most proud of our riders who endured the heat, wind, driving thunder storms, hills and associated aches, pains and missing equipment in their valiant 3-day ride of 210 miles ... UOAA's cycling all stars: Bob Baker, Brenda Elsagher, Julielyn Gibbons, Charlie Grotevant, Emily Mallar, George Salamy, and our friend from Hollister, Mark Kennedy.

In 2007 there are three, 3-day cycling challenges:

- Ride #1 in Central Texas, LaGrange to Austin, March 23-25;
- Ride #2 in the Hudson Valley, New York City to Saratoga Springs. June 8-10; and
- Ride #3 in the Pacific Northwest, a scenic loop of Whidbey Island & the Skagit Valley, August 3-5.

For more details about how to enter as a rider or crew member, visit the GYGIG website at [www.IBDride.org](http://www.IBDride.org). To show UOAA's support of this project and to encourage more of your members to "take the ride", UOAA will pay the \$ 85 registration fee for each rider or family member who rides or crews in any of these 3 events. Page 5 is an information flyer that you can distribute to your interested members.

## ❖ Newsletter Editor Directory

To assist in getting the word about UOAA out to your membership, UOAA is compiling a **Directory of Newsletter Editors**. These editors, in addition to the AGS contacts, will receive a copy of these UOAA UPDATES when they are published. In this way, information such as National, Network and Regional Conference Flyers, Advocacy Alerts, **The PHOENIX** subscription advertising and articles of general interest can be made public. To help us complete this Directory, you will be receiving a letter from Joan McGorry in the not too distant future asking for your editor's name and contact information.

## ❖ Website – [www.uoaa.org](http://www.uoaa.org)

What do you think of our website? Is it meeting your needs? What do you suggest we do to improve it. Is there a page, a feature, or something that you would suggest be added. In the near future we will send you a "**Website Survey**" upon which you can record your opinions. We need your input to ensure that the UOAA website is meeting the needs of the ostomy community and the interested public in general.

## ❖ Phoenix Renewals

As a heads-up, the next issue of **The Phoenix** magazine will be mailed on December 15<sup>th</sup> and should reach your members within 5 to 10 days.

A good number of your members have been receiving subscriptions of **The Phoenix** magazine for the past year and it is now time for them to renew their subscriptions. As a bonus for renewing for another year, there will be boxes on the renewal form that can be checked off if the subscriber wishes to receive a "gift" from Coloplast, ConvaTec, Cymed or Hollister.

Speaking of **The Phoenix**, a review of the ASG newsletters that are sent to me showed that just 1 in 4 of them advertises UOAA's excellent magazine to their members. We know that the magazine may be mentioned in other ways (a flyer at meetings or in with visiting materials), but we also know that the newsletter may get into many other hands that need to know about ALL the available resources for help. PLEASE ask your editor to make use of the ads that editor Ian Settlemire has prepared – there's a size for every newsletter format. THANKS for taking care of this, and for helping all your members to know about **The Phoenix**.

## ❖ Awards

What is an organization without awards? Following in the tradition started by UOA, UOAA will honor a **WOC Nurse** each year for outstanding service to their local ostomy community and to their local ASG. In my next UPDATE I will be able to provide you with more details about how to go about nominating your group's most deserving WOCN. We are in the process of appointing a stellar committee to manage the award proceedings. It is our intent to present the Award to the recipient at the WOCN National Conference, and again at the UOAA National Conference.

The second award that has been approved by the MBoD is an **ASG Leadership Award**. This award will be presented to 4 ASG leaders, each from a different Region of the US. Nominees for this award will have demonstrated outstanding leadership skills and commitment to ostomy rehabilitation at the support group level. ASGs will be invited to nominate award candidates. The nominations will be reviewed by a panel of former leaders and the first awards will be presented at the UOAA National Conference this August in Chicago. More details will be forthcoming in the next UPDATE, but it is not too soon to think about whom you would like to nominate.

### ❖ The Colon Club

My first exposure to members of The Colon Club leadership was this past June at the New York City start of the GYGIG ride. The Colon Club, like UOAA, is a beneficiary of the rides' proceeds. The Colon Club was founded in 2003 by Molly McMaster, 28, a colon cancer survivor who was diagnosed on her 23rd birthday, and Hannah Vogler, 30, whose cousin and Molly's friend, Amanda Sherwood Roberts, died of the disease at the age of 27. Its main goal is to educate as many people as possible, as early as possible, about colorectal cancer in interesting and out-of-the-box ways. Their wishes are for people to have "colon talk" in their everyday lives, to know the risk factors and symptoms, and to get screened when it is appropriate for them. The Colon Club has two innovative projects. For educational purposes they have designed and schedule trips for "CoCo", the Colossal Colon. CoCo is a 40-foot long, 4-foot high model of the human colon. People who crawl through it will see Crohn's Disease, ulcerative colitis, diverticulosis, hemorrhoids and cancerous and non-cancerous polyps. Since 2002 CoCo has appeared at events in 74 cities, in 34 States and Canada. The other project, a fundraiser, is the production and sale of its "Colondar", a calendar using "young" colon cancer survivors as models. UOAA Vice President-Elect, Bob Baker appears in the 2007 Colondar as "Mr. December" and on the cover in the upper right hand corner. See the Colondar website for a sneak peek at this great fund raising product. <http://www.colonclub.com/colondar.html> The UOAA MBoD has agreed to sponsor a month in the **2008 Colondar**. In addition to nominating a colon cancer survivor model, information will appear in the Colondar about UOAA and its ASG members. You will be hearing more about this project as the New Year begins. (See Colondar link on the UOAA home page.)

### ❖ Ostomy Product Donations

From time to time we are asked by ASG leaders what to do with surplus ostomy products that have been donated to the group. Surplus supplies can always be helpful to someone. There are actually 2 options. You have probably heard of **Friends of Ostomates Worldwide - USA**. They send surplus supplies to medical facilities in other parts of the world, for distribution to patients who cannot afford their own - usually in underdeveloped countries.

The FOW-USA website is:

[www.fowusa.org](http://www.fowusa.org) and their mailing address is  
FOW-USA  
4304 Regency Drive  
Glenview, IL 60025

There is also an organization very much like FOW-USA that distributes surplus items to people here in the US who don't have insurance to cover their supplies (we hear from or about them quite often). **Osto-Group** asks only for 10% of the value of the

items, to help cover their shipping expenses. If you want to check out their website, it is:

[www.ostogroup.com](http://www.ostogroup.com) . Osto-Group is run by one of UOAA's affiliated support groups (Nevada County, CA). Their address is:  
Osto Group  
18962 Lake Forest Dr.  
Penn Valley, CA 95946-8818

### ❖ Bladder Cancer Advocacy Network

As we see the number of people with urostomies increase in our support groups we also recognize that we are lacking information to pass on to these folks. In 2005, BCAN was organized. BCAN is a national patient-based public awareness and educational activities organization for bladder cancer. The website for BCAN is [www.bcan.org](http://www.bcan.org)

## ADVOCACY:

UOAA hopes to find a more receptive audience with the newly elected Congress, to hear our arguments about how Medicare reimburses ostomy supplies, both for people receiving home health care services and for those getting their supplies through Part B of Medicare. We are following developments in the State of California, which will begin to test a new system in mid-2007 for reimbursing supplies under the MediCal program (for low-income persons). We are also monitoring developments in Pennsylvania, as well as keeping our eyes open for proposed changes in other state Medicaid programs.

We would like to identify at least one person in every state to serve as an advocate for UOAA on issues that arise there. It could be issues such as insurance, colo-rectal cancer screening, even bathroom access. Please contact Linda at [advocacy@uoaa.org](mailto:advocacy@uoaa.org) if you are interested or know of someone who is.

The Digestive Disease National Coalition: Linda Aukett represents UOAA in DDNC, whose purpose is to lobby for research and education funding for the National Institutes of Health and the CDC. At their Annual meeting she was elected one of 4 directors-at-large of the Executive Committee. **In March '07, DDNC will hold their annual Public Policy Forum. ALL interested persons are invited to participate, either in Washington or in their home district - contact Linda for details.**

## UPCOMING EVENTS / MEETINGS:

### ❖ 2007 National Conference

At a Conference Planning Meeting held earlier this month at the Lincolnshire Marriott Hotel in suburban Chicago, there was quite an air of excitement about this upcoming event. Conference Chair Kristin Knipp will have a flyer and registration form on the website by early next year. Here is some information that I can give you now, to convince you to be part of it all:

The Registration Fee will be \$ 75 per attendee ... \$ 25 for companion ... Children under 10 free

Hotel room rate is \$ 109/night/SD + \$ 11.99 tax

Jane Michnik has agreed to serve as the Local Conference Chair;

Events will start Wednesday, August 15<sup>th</sup> with a Golf Outing on the hotel's Crane's Landing Course at noon. Outing Chair is Renard Narcaroti;

Wednesday evening, Hollister will provide transportation to their Corporate Offices at nearby Libertyville for a cookout, country music and tour of their facilities

The opening session will start at 9:00 am Thursday

The Exhibition Hall will be open from 2:15 to 6:00 pm

The ConvaTec Evening Social will begin at 6:30 pm

The Exhibition Hall will reopen Friday at 8:30 am

ASG Leadership Meeting will start at 8:30 am

A Recognition Luncheon will start at 11:45 am

Educational workshops will start at 2:00 and continue until 5:30 pm

Friday evening no activities are scheduled

Educational workshops Saturday start at 8:30 am

Closing Session will be 3:30 to 5:00 pm

Informal Reception, Banquet and Entertainment start at 6:30 pm

#### ❖ **IOA's 12<sup>th</sup> World Congress**

The UOAA delegation to the 12<sup>th</sup> World Congress, in Puerto Rico, 7-12 August 2007, will include Ken Aukett, Kristin Knipp and Bob Baker. Join us!

#### ❖ **IN MEMORIAM**

It is with a great deal of sorrow that I must mention the loss of three dear people.

For those with deep roots in UOA, the name of **Gene Galindo**, Nu-Hope and the annual Conference Fun Run were interchangeable. Gene, one of UOA's long-standing Industry Advisors, the founder of Nu-Hope, was dedicated to ostomy rehabilitation as evidenced through his commitment to nurse training seminars and support of UOA's mission coupled with his desire to see the programs and activities in place that would make the organization successful.

If ever there was a person who typified the word "humanitarian", **Cy Smith** was that person. I don't believe I ever heard a harsh or negative word uttered by or about Cy. Dedicated to his soul mate, Dorothy, he was a compassionate, soft-spoken person who would work tirelessly on a project or cause in which he was involved.

**Barbara Salamy**, what a beautiful, spirited woman ... she was a fun person to be with ... possessed a smile that

would light up a room ... but yet was deep in her ability to understand your problems and communicate advice and counsel that would help you get through the tough times. Through George's involvement with UOA, we had a chance to know her, to learn from her and to enjoy her company. Barbara's world was complete ...devoted wife, mother, grandmother, active in her church and a picture of hope to children on the island of St. Kitts where the nursing group she organized provided medical care for those in need.

- ❖ **IN CONCLUSION** ... With the holiday and flu seasons upon us the thought for the day is ... rest, avoid crowds, drink lots of water, and enjoy the moment. 2007 will come soon enough!

With warmest wishes,  
**Ken Aukett** - President, UOAA