



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.

**APRIL 2007**

## **UPDATES:**

### ❖ **Distribution of UOA Assets**

As part of UOA's "Going Out Of Business" process the Superior Court of New York (the State in which UOA is incorporated) and the IRS required UOA to distribute its remaining financial assets to not-for-profit organizations that have 501(c)(3) Charity Status. The UOA Board of Directors determined that the following organizations would participate in this asset distribution: **The Youth Rally Committee, Inc; The Pull-Thru Network, FOW-USA, Get Your Guts In Gear, Inc.**, and **Goldie's Fund**, in addition to UOAA.

UOAA's portion amounted to a check for **\$ 130,000**, and a note for a building formerly owned by UOA at 2001 W. Beverly Boulevard, Los Angeles valued at **\$ 306,000**. I am pleased to advise that this note was paid off and a check received in the full amount during the 3<sup>rd</sup> week in April. As a result of this action by UOA, UOAA is in a solid financial position.

### ❖ **Fall 2007 Election**

In the election we will have later this year, there are three candidates for Director who are vying for two seats on the Management Board of Directors. The candidates elected will serve for a two-year term commencing January 1, 2008 and expiring December 31, 2009. There are four Directors on the UOAA MBoD, each serving a two-year term. There terms are staggered so we will be electing two Directors every year. Directors can be re-elected once. This year's candidates are **LeeAnn Barcus, Michael Guss** and **Steve Strizic**. Both LeeAnn and Steve are presently on the MBoD and are seeking re-election. **Ginnie Kasten** will continue to Chair the Nominations and Elections Committee.

❖ **Affiliated Support Groups** – Since our last UPDATE in February the number of support groups that have affiliated with UOAA now totals 239. We are most pleased to welcome **FOW-USA** as our latest affiliate. As I trust you are aware the mission of **FOW-USA** is to ship donated ostomy supplies to people in need throughout the world. By affiliating with UOAA it is expected that the public awareness of their goal and their fund raising capabilities will be increased. Funds are needed to ship the supplies to foreign destinations.

You can view the entire list of affiliates at:  
<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.

**We would like to send this UPDATE to a  
2<sup>nd</sup> member of your support group!  
Please e-mail Joan with their name and  
contact information – thank you!**

### ❖ **IRS Application for 501(c)(3) Charity Status for ASGs**

UOAA submitted the paperwork to have designated ASGs included under UOAA's 501(c)(3) Charity Status, as requested by the IRS, by the due date of April 4<sup>th</sup>. This was part of the continuing process that starting in June 2006. If the IRS approves of our submission they will again request us to submit designated paperwork for their review and approval. To date, I have not heard from the IRS regarding the review of our April 4<sup>th</sup> submission. When I receive word from them, which should come any day now, I will communicate the news, good or bad, to all ASG leaders.

### ❖ **Awards**

#### **ASG Leadership Award**

There still is time for you to nominate that outstanding person in your support group that has been volunteering their time and talents to make the world a better place for ostomates in your service area.

UOAA is giving you the opportunity to submit nominees for the **2007 ASG Leadership Award**. Four (4) awards will be presented to those nominees determined by the Award Committee (**Charlie Grotevant**, Chair) to be most deserving. Attempts will

be made to spread the awards around the country, if possible. These Awards will be presented every other year in conjunction with UOAA's National Conferences, with the first awards presented at the Lincolnshire, Illinois Conference, at the Recognition Luncheon, on August 17. Each Award recipient will receive a complimentary conference registration, a Luncheon ticket and \$ 250 towards their travel expenses. Announcement of the Award recipients will be made by July 1<sup>st</sup> to ensure that the recipient or their representative is in attendance at the Conference.

**ATTACHED IS A FORM FOR YOUR SUBMISSION. APPLICATIONS MUST BE RECEIVED BY JUNE 1<sup>ST</sup>, 2007.** Submit the form to Joan McGorry by email: [oa@uoaa.org](mailto:oa@uoaa.org) or mail it to ASG Leadership Award Committee. P.O. Box 66, Fairview, TN, 37062, or Fax to: 615-799-5915

❖ **Website News**

With more and more people using the Internet to obtain information about medical conditions, it is imperative that UOAA have a website that best serves the needs of UOAA, our affiliated support groups, the ostomy community and the general public at large.

We are certainly proud of [www.UOAA.org](http://www.UOAA.org) and what our Webmaster Bob Baumel has done in creating it, however we cannot afford to rest on our laurels. To ensure that [www.UOAA.org](http://www.UOAA.org) is "all that it can be" an ad-hoc Taskforce has been appointed to examine the "look" of our site, the information that is displayed and the manner in which it is delivered. Thanks to an Educational Grant from Hollister, professional guidance in the planning phase will be provided to the Taskforce by their Webmaster and web consultation service.

A meeting of the Management Board of Directors will take place on May 18<sup>th</sup> at the Hollister Corporate Office in Libertyville to review the Taskforce's progress and to provide them with further direction.

❖ **ASG Leadership Resource Program**

Since this Program was announced in the February UOAA UPDATE, **Steve Strizic**, who is chairing the LRP, sent a letter to all ASG contacts. The following is a follow-up letter from him .....

"Hi folks,

I want to thank everyone who e-mailed me with their comments in response to the letter I sent to all our ASG leaders about the development of the LRP. I have compiled a list of topics reflecting your comments and to let you know we are putting them to good use. (See list below)

I know many of our groups are quite successful in the things they do and would like you, now, to let us know what these successes are. I would like to be able to

use them in the development of the LRP and to share them with the other ASGs.

So please tell me of one or two things that your group does well and how you accomplish them. As I said in my first message to you, this Program is yours and we want it to be of help to every group.

Thanks, Steve Strizic, [steves@uoaa.org](mailto:steves@uoaa.org)

The following is a list of topics for which we are seeking experts ... who will be able, when the LRP is ready to go, to provide you with good information about these subjects:

- How to start and develop a website
- Newsletter publishing tips—printed
- Newsletter publishing tips—web based
- Advocacy Issues
- Insurance
- Discrimination
- How to work with local Home Health Care Agencies
- How to work with local medical communities.
- Non-profit (501(c)(3) questions.
- How to participate in community Health Fairs.
- How to work effectively with other local Health oriented non-profit organizations.
- UOAA Questions
- General questions
- Special programs
- Planning a Regional Conference
- General Support Group Issues
- How to start an ostomy support group or an Outreach group
- Declining group membership - membership retention; attracting new members
- Regular meeting program ideas
- Leadership recruitment and revitalization
- Developing a good Patient Visiting Program

❖ **Regional Leadership Seminars**

UOAA's first Regional Leadership Seminar has been tentatively scheduled for Saturday, November 17<sup>th</sup>, 2007 in the Santa Ana/Irvine/Mission Viejo vicinity of southern California. This Seminar will be sponsored by Coloplast. More details will be communicate to you when they are available.

❖ **Get Your Guts In Gear (GYGIG) Rides**

GYGIG's Rides provide participants the experience of overcoming physical and mental challenges within a supportive Ride Community. By completing the Ride, many riders (novice and experienced alike) accomplish a goal beyond any achievement they had thought possible. The first GYGIG Ride of 2007 in the hills from LaGrange to Austin, Texas is now history. Congratulations to **Ian Settlemire**, publisher of **The Phoenix** for completing this ride in style, and 'thank you' to UOAA Office Administrator **Joan McGorry** for representing us in Austin.

**MORE GYGIG:** Next up is Hudson River Valley Ride, from New York City to Saratoga Springs, on June 8-10. Riding in this event will be: Bob Baker, # NY30 and Bob's son, Chris Baker, # NY31; Julielyn Gibbons, # NY51; Charlie Grotevant, # NY52; and Paul Warning, # NY80. Each rider is charged with raising \$1,900. If you wish to sponsor a rider click on "donate" on the GYGIG website, [www.ibdride.org](http://www.ibdride.org). UOAA is a beneficiary of this fund raising event. Last year UOAA was presented a check by Judy Pacitti, GYGIG Ride Director, in the amount of \$ 47,000.

Ride #3 will again be in the Pacific Northwest with riders making a scenic loop of Whidbey Island & the Skagit Valley on August 35. I will give you more information about the UOAA participants in this ride in my next UPDATE. Keep in mind, UOAA will pay the entrance fee of anyone who either wants to ride or crew in any of the GYGIG rides. AND riders will get a new "Team UOAA" hat to display their team spirit.

#### ❖ **Newsletter Editors, Note!**

The following was written by Doug Graham, President of UOA Canada in his column that appeared in the UOAC February 2007 Newsletter entitled "To Copy or Not – Copyright Laws"

"Many chapter newsletter editors find an article they believe will be helpful to their members and enthusiastically reprint it in their newsletter. On many occasions credit is given to the source and no concerns are expressed. On January 23, 2007, I received an e-mail from G. Attara, Executive Director, Canadian Society of Intestinal Research. The complaint is that the article, "Pregnancy and Ostomies" was included in the December 2006 monthly newsletter from the Toronto Chapter, who 'credits' the Ileo Info Bulletin in Montreal. The original article was published under copyright in issue 156 (July/August 2006) of 'The Inside Tract'. The email continues: *"Our Society has contacted various chapters over the years regarding copyright infringements but this practice still has not ceased. This is your final warning. Should the United Ostomy Association or any of its chapters commit any further violation, we will immediately proceed with legal action. To avoid further difficulties, we ask that you consult us with any re-publishing request."* I have responded to G. Attara that I will stress that all Editors must get a written agreement before copying anybody's work. Editors, please ensure that you confirm the right to re-publish any articles you find that you want to include in your Chapter Newsletter. I personally believe that there is no disrespect intended here, only eagerness to inform others."

#### ❖ **2007 National Conference:**

##### □ **"Room Information"**

Our Conference starts with a golf outing on Wednesday afternoon and a Hollister Open House that evening, August 15<sup>th</sup>. The official Conference opening is Thursday morning. People trying to reserve a room for Tuesday night, August 14<sup>th</sup> are being told by the Marriott reservationist that there are no rooms available at the Conference rate of \$ 109. This is correct, but it only applies to Tuesday night. **There ARE rooms available at the \$ 109/night rate Wednesday through Saturday.** For those that want to come on Tuesday and do not want to pay the \$ 249/night rate the Marriott is charging, we are investigating nearby hotels where the rates are lower ... I will advise you about these hotels in my next UPDATE.

##### □ **"Programming"**

Attached is a flyer that shows you the programming that we have planned for the Conference. There will be programming for the General audience as well as targeted programming for the 30+ Network, the Young Adult (YODAA) group, those with Continent Diversions the Teen Network, Gay and Lesbian Ostomates, and The Pull-Thru Network aimed at parents with children who have ostomies or other diversions.

The Keynote speaker for the Opening Session will be Paula-Erwin Toth, Director of the ET Nursing Education Program at the Cleveland Clinic, a person who has had a stoma since she was an infant.

Our Closing Session will feature a presentation by Craig Wilson. Craig's life story is documented in an award winning DVD entitled "**Farang Ba**", a Thai phrase that translates into English as *Crazy White Foreigner*.

**UOAA would like your ASG to have a copy of this DVD.** It can be used to promote the Conference, as a great monthly educational program, and can be loaned out to new ostomates to demonstrate that there is truly nothing we can't do!

To get your free DVD contact Joan McGorry at [oa@uoaa.org](mailto:oa@uoaa.org) or give her a call at 800-826-0826. We are asking that you pay a \$ 2.00 packaging and postage charge.

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

On August 7<sup>th</sup> through the 12<sup>th</sup>, 2007, The International Ostomy Association will be holding its **12<sup>th</sup> World Congress** at the Fajardo Inn, in Fajardo, Puerto Rico.

For **details about the Congress** check out the following page of IOA's website:

[www.ostomyinternational.org/12congress2007.htm](http://www.ostomyinternational.org/12congress2007.htm)

For **details about the hotel** go to the following website: [www.fajardoinn.com](http://www.fajardoinn.com)

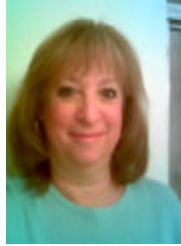
And for a **registration form**, click on:

[www.ostomyinternational.org/Forms/2007CongressRegistration.pdf](http://www.ostomyinternational.org/Forms/2007CongressRegistration.pdf)

**UOAA'S MANAGEMENT BOARD:  
Up Close and Personal:**

**Introducing Lynne Kramer.....**

“ I first joined UOA in 1977 after my ileostomy surgery for ulcerative colitis. Since that time, local support groups have been my lifeline. I have been active both locally, as a secretary and treasurer, and nationally, as a member of the 30 Plus committee, chair of the Continent Diversion network and, proudly, as a member of the board of directors of UOA and now UOAA.



In 1990, my Brooke ileostomy was changed to a Kock pouch. I have found that having had both surgeries gives me a unique perspective and ability to relate to many different ostomates.

Interaction with others, whether it be in person, on the telephone, or even by email or in a discussion forum, is, and always will be, an invaluable service that we provide to each other. Talking to other ostomates from all over the country and meeting some of them at national and local conferences has been an opportunity that I wish everyone could have at some time. My most rewarding experiences have come from helping others going through similar experiences. The chance to serve as a Youth Rally counselor has most definitely changed my life and provided some experiences I will never forget.

I have been teaching for more than 30 years. In addition to the time I contribute to UOAA, I love playing golf and tennis, going to movies, Broadway shows and concerts.

**And, Charlie Grotevant .....**

“ I was diagnosed with chronic ulcerative colitis in 1977, at the age of 35. After several years of flare-ups, increasing in intensity and duration, ileostomy surgery was performed in November 1983. I joined the Kankakee Ostomy Association following surgery, and became active in the support group in 1990, as an officer and ostomy visitor. Active involvement continues, as support group leader and lead visitor.

Joyce and I are celebrating 45 years of marriage this April, and are becoming less active in the day-to-day activities of our Illinois farm. We have 3 adult children and 5 grandchildren. A son-in-law and grandson have taken on leadership roles of the farming operation producing corn, soybeans, and wheat.

In the spring of 1983, during a remission stage of the ulcerative colitis, I began running with the hope that better physical conditioning would help my body ward off the flare-ups. However, another flare-up put me in the hospital for the fall harvest season, leaving me with the realization that the only way to continue farming would be with an ileostomy.

My health improved even more that I ever imagined because of the surgery. I returned to running in 1984, for physical fitness and to celebrate my new life, free of disease and healthy for the first time in years. The fitness running evolved into racing with membership in running clubs to the extent that I have completed more than 860 road and trail races and logged nearly 40,000 miles wearing an ostomy pouch.

In 2000, I added bicycling to my fitness regimen. The activities of being a farmer, runner and biker led to recognition as the 2002 recipient of the Great Comebacks Award, recognizing annually people who have led active lives following ostomy surgery.



In 2006, Joyce and I participated in the GYGIG 3 day Seattle bike ride, me as a rider, and Joyce, driving our van, as part of the support crew. We are registered for the 2007 GYGIG 3 day ride in New York, again Joyce crewing and me pedaling.

Following the announcement of the dissolution of UOA in 2005, I accepted Ken Aukett's invitation to help in the formation of UOAA and serve as a Director. My involvement with UOAA and the Kankakee Ostomy Association is my way of paying back those who helped me during years of illness and supported me when I began my life as an ostomate. It's the "obligation of the cured".

❖ **IN CONCLUSION** ... What a wonderful time of the year Spring is ... when I started writing this UPDATE the flowering bulbs were in bloom ... then it snowed and almost froze them ... high winds tried to knock them over and a Nor'easter nearly drowned them ... yet today when I looked in the garden there was a sea of purple violets! My back yard is like our life experiences ... things are good for a while, then old Mr. Fate tosses a few curve balls in our direction ... but we hang in there and sure enough, our world gets its act together and all is right again! See you in August!!

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