



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.

FEBRUARY 2007

UPDATES:

❖ Fall 2006 Election of UOAA Management Board of Directors

For those that may have missed the election results as announced by **Ginnie Kasten**, Chair of UOAA's Nominations and Elections Committee, your Management Board of Directors now consists of:

Officers whose terms expire December 31, 2009 ...

Ken Aukett, President, **Kristin Knipp**, President Elect; **Bob Baker**, Vice President, **Dave Rudzin**, Treasurer; **Mary Jane Wolfe**, Secretary.

Directors whose terms expire December 31, 2008 ...

Charlie Grotevant, **Lynne Kramer**

Directors whose terms expire December 31, 2007 ...

LeeAnn Barcus, **Steve Strizic**

An Educational Grant by Hollister Incorporated funded a Strategic Planning Meeting at their facilities in Libertyville, Illinois this past January where members of the newly formed UOAA MBoD had an opportunity to launch several new programs designed to strengthen our Affiliated Support Groups. (Details appear later in this UPDATE)

Board of Trustees, appointed by the MBoD, whose terms expire December 31, 2009:

Chair: **Ron Titlebaum**

Members: **Sherry Lessard** and **George Salamy**

❖ Fall 2007 Election of UOAA Directors

In accordance with UOAA's Constitution, an election will be held this Fall to elect two Directors. These Directors will be elected for a 2-year term, expiring December 31, 2009. You have until **April 20th, 2007** to nominate candidates for this office. This is your opportunity to participate on the national level in a humanitarian organization that is trying to improve the quality of life of all who have undergone bowel and urinary diversions. Come on in, the water is fine!

❖ Affiliated Support Groups – Since our last UPDATE in November the number of support groups that have affiliated with UOAA now totals 232, and when you include the Outreach Support Groups, UOAA now represents **248 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

Requests for visitors received on

ostomyvisitor@uoaa.org will be forwarded

by Joan to the nearest ASG.

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

❖ UOAA Flyer

Attached for your use, as you think appropriate, is a two sided, [UOAA, tri-fold flyer](#). It is sent to you in "MS Word" format so that you may customize it by adding your support group's name and contact information.

❖ Annual Affiliation Fee (AAF)

Notices have been sent to all ASGs regarding payment of the 2007 Annual Affiliation Fee. The Fee for 2007 is **\$ 2.00 times the unaudited number of members in your group** that you reported previously to UOAA. Groups that reported "no members" are charged a flat fee of \$ 25.00. On February 26th a reminder e-mail notice will be sent by Joan McGorry to those groups from whom a fee has not been received. This will be followed by a telephone call the week of March 12th to determine if the group is still interested in being affiliated with UOAA.

❖ Phoenix Renewals

There is still time to renew your subscription to **The Phoenix** magazine and receive the bonus gifts from Coloplast, ConvaTec, Cymed or Hollister. Remember, half of the \$ 25 subscription fee helps fund UOAA activities and as such is tax deductible.

AWARDS:

WOC (ET) Nurse of the Year

Is there an outstanding WOC Nurse in your support group that you would like to honor by putting their acts of professional dedication to our ostomy community in the national spotlight?

UOAA is requesting its ASGs to submit nominees for the **2007 WOC (ET) Nurse of the Year Award**. This award will be presented to the recipient at the WOCN Conference, June 10 to 13, 2007 in Salt Lake City, UT in the presence of their peers, and again at the UOAA National Conference in Lincolnshire, Illinois at the Recognition Luncheon on August 17th. The recipient will receive travel expenses to the UOAA Conference, a hotel room for 2 nights, and conference registration. 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 15TH, 2007. Submit the form to *Jan Clark*, 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

ASG Leadership Award

Now is your chance to honor that person in your 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 its ASGs an 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.

APPLICATIONS MUST BE RECEIVED BY JUNE 1ST, 2007. Application forms were distributed to Affiliated Support Groups in February 2007. Submit the form to Joan McGorry by e-mail: oa@uoaa.org or mail it to ASG Leadership Award Committee. P.O. Box 66, Fairview, TN, 37062, or Fax to: 615-799-5915

❖ **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

ASG contacts, will receive a copy of these UOAA UPDATES when they are published. To help us complete this Directory please provide Joan McGorry with the name and contact information for your Editor.

WEBSITE NEWS – www.uoaa.org:

All support groups have been asked to provide an e-mail address so that we can communicate (like sending this Update). The list of contact names and e-mail addresses is also on our website so that people who need ostomy help in your community can locate your group. We understand that, unfortunately, there are commercial entities whose mission is to provide you with unsolicited information, aka "**SPAM**". Please understand that we have taken steps to limit this **SPAM** that might reach you through this listing on our website. If you view this page (see the link on page 1) you will see that we ask that this list not be used for commercial messages. We are aware, however, that some business people have ignored our request. The commercial-oriented messages you have received recently **were not authorized by UOAA**. I hope you will note that we have posted a message to folks intent on doing that, telling them of more effective ways to reach you and your members. We continue to look for ways to protect these addresses while still making it possible for people who need help to find you.

A new **Irrigation Discussion Board** has been added to our website. When the Message Boards on the Evansville website were closed down, we received numerous requests from participants there asking that UOAA create a forum dedicated to this topic.

The UOAA MBoD has authorized the formation of a study committee **to look into ways the UOAA website can be enhanced**. This will be a work in progress with results visible by year-end. Members of this Committee include our webmaster, *Bob Baumel*, *Linda Aukett*, *Joan McGorry* and Hollister's webmaster, *Jim Paul*.

PARTNERS IN OUR WORK:

❖ **Coloplast Meeting**

On Ground Hog's Day, February 2nd, I was afforded the opportunity to meet with Coloplast's new USA Ostomy Sales and Marketing senior management and staff at their new offices in Minneapolis, Minnesota. The wind- chill factor outside was minus 15, but inside it was warm and most cordial. I can report that Coloplast is most supportive of UOAA's efforts to communicate with new ostomates, of our plans to conduct Regional Leadership Workshops, and of our efforts to promote subscriptions to *The Phoenix*, and Coloplast will have a notable presence at our upcoming National Conference.

❖ **The Simon Foundation for Continence, USA**
 UOAA has established a working relationship with The Simon Foundation for Continence, USA. Cheryle Gartley is the founder and President of this Wilmette, Illinois based organization (visit their website at www.simonfoundation.org) The Simon foundation addresses the “**stigma**” that society places on the 43 million people in the United States with disabilities, especially those with urinary and fecal incontinence. The Simon Foundation will have a booth at our Conference this August and Cheryle will present a workshop about “Living with Quiggles”.

❖ **Colon Cancer Alliance**
 UOAA has been invited by the Colon Cancer Alliance to exhibit at each of 10 events they are holding around the country, called “Conversations about Colorectal Cancer”. We will be contacting affiliated support groups in the intended locations to invite you to help represent UOAA at these important events.

❖ **LEADERSHIP RESOURCE PROGRAM**
 In order for UOAA to be successful, it is imperative that the ASGs be as strong as possible. Strong groups require strong leadership and UOAA must take steps to ensure that this continues to happen.

UOAA is presently undertaking the development of a “**Leadership Resource Program**”. The intent of this program is to assist Support Group leaders to resolve management problems and to provide ideas about how the group’s services can be advanced. UOAA will recruit a team of advisors, each with the ability to address one subject. For instance there will be someone who will be able to give you advice on how to get members of your local medical community to refer their ostomy patients to your group, or to utilize its Patient Visiting service. Others will answer questions such as: “What steps do I have to take to develop a working relationship with our area’s Home Health Care Provider”? “How can I publish an electronic newsletter”? “How can I use the internet to promote our services”? We will have people on the **LRC** who can answer questions about monthly programs, how to identify and recruit future leaders, run a good health fair, and many more topics. The ASG contacts will be given a “menu” of topics, the names of “experts” and how to contact them. This menu will be published and maintained on www.uoaa.org.

One expert, one subject, one answer. We believe this is a cost effective way for UOAA to provide its ASGs with useful, timely management assistance. This program will be coordinated by **Steve Strizic**.

❖ **REGIONAL LEADERSHIP WORKSHOPS**
 Another approach UOAA will employ, designed to strengthen the ASGs, is to convene **Regional**

Leadership Workshops. At these one day seminars, leaders and potential leaders from support groups in one geographical area will be invited to participate in a setting that will feature topical presentations and an opportunity for the attendees to interact in a moderated forum discussing issues of common concern. This concept has been discussed with Industry representatives and it is anticipated that Educational Grants will be received. Industry recognizes the importance of the service that the ASGs are providing and wants them to succeed.

ADVOCACY:

❖ **Hot Issues:**
 The current major concerns are:
 - whether ostomy supplies will be included in Medicare competitive bidding in 2008 (local suppliers and national mail order houses submit bids in their metropolitan areas), UOAA is working to improve our chances of being exempt from competitive bidding through the Tanner-Hobson bill. Also, UOAA is joining The Coalition to Ensure Beneficiary Access (CEBA) in its fight against competitive bidding in its current form.
 - Medicare home health care consolidated billing, Many home health agencies are not doing their job in compliance with federal regulations (which is one of the reasons that Hollister created their Secure Start Discharge Program).
 - and states, such as California, Florida, and Pennsylvania, threatening to cut back on Medicaid.

❖ **Digestive Disease National Coalition (DDNC) Participation:**
 The DDNC **Public Policy Forum** will be held in Washington, DC, on March 11 & 12. Only a small portion of attendee expenses can be covered by UOAA, but volunteers are being sought to attend. The first afternoon will be spent giving the attendees orientation on the current issues. The next day appointments will be made for teams of people to meet with legislators on Capital Hill.

❖ **State Advocates:**
 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 if you are interested or know of someone who is.

TIMELY PRODUCT NEWS:

Smith & Nephew announced early this month that their SKIN BOND product has been discontinued. Most recently they reformulated the product by removing latex (so that people with a latex-sensitivity could use it) but now they will not manufacture it at all. Bear in mind that there are supplies of Skin Bond still on the shelves at suppliers around the country (both with and

without latex), so it will be a while before the stock is completely depleted - but that gives you time to find something else that will work for you.

Here are some suggestions about similar products:

Nu-Hope Adhesive is a non-latex product: see <http://www.nu-hope.com/xccess/add.html>

Torbot Bonding Cement (with latex) can be bought on-line or thru a catalog:

<http://www.torbot.com/view/featured/147/>

Torbot also has Skin-Tac:

<http://www.uoaa.org/forum/viewtopic.php?t=4681>

Montreal Ostomy Supply has OSTO BOND (with latex) at <http://www.montrealostomy.com/page2.html>

Medical adhesives that rarely get advertised in the ostomy media can be seen at:

http://www.factor2.com/catalog/medical_175308_products.htm

An old stand-by, Tincture of Benzoin provides 'tack' and has some protective properties if you have sensitivity to adhesives. Read more about it here: http://www.drugs.com/cdi/benzoin_tincture.html

Bruce Medical is one source for this:

<http://www.brucemedical.com/bentin.html> (DO NOT confuse it with straight benzoin, which would be most unhealthy to apply to your body).

UPCOMING EVENTS / MEETINGS:

❖ GYGIG Ride

It's hard for some of us to believe with all of the snow and ice on the ground, but the first GYGIG cycling event will take place in Central Texas in less than a month, March 23-25 to be exact. Judy Pacitti, GYGIG Ride Director, assures us that it will be a beautiful time to ride through the hills from LaGrange to Austin surrounded by fields of spring flowers. Each of the event riders is committed with raising a minimum of \$1,900 from sponsors. Representing UOAA in the Texas ride is *Ian Settlemire*, publisher of *The Phoenix* magazine. If you would like to sponsor Ian, click on his name at uoaa.org/gygig.shtml. Ian's rider number is TX05.

Ride #2 will be in the Hudson River Valley, New York City to Saratoga Springs, on June 8-10; Ride #3 will again be in the Pacific Northwest with riders making a scenic loop of Whidbey Island & the Skagit Valley on August 3-5.

We will provide you with more information about the UOAA riders in Rides # 2 and 3 in my next UOAA UPDATE.

For more details about how to enter as a rider or crew member, visit the GYGIG website at 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.

❖ 2007 National Conference:

If you are planning to attend UOAA's inaugural National Conference, August 15 through the 18th, at the Lincolnshire Marriott, just outside of Chicago, I suggest that you book your hotel room as soon as possible. Since this is UOAA's first National Conference the hotel room block is smaller than the room block UOA secured at previous conferences.

For a conference flyer and registration form with all the details, click on

http://www.uoaa.org/conference_2007.shtml

If you read the last issue of *The Phoenix* magazine, then you are familiar with the name Craig Wilson. Craig appeared on the cover and the feature article about his life as a middle-aged lawyer by day, and an amateur boxer by night. This saga about an American in Thailand is truly inspiring and unbelievable. I am most pleased to tell you that Craig will be our speaker at the Saturday afternoon closing session.

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 or give her a call at 800-826-0826. We are asking that you pay a \$ 2.00 packaging and postage charge.

❖ 2008 ASG Regional Conferences:

How would your ASG like to **host a Regional Conference** next year? UOAA can provide logistical support to those groups that are interested. If your group would like additional information about hosting one, please contact me at kenaukett@uoaa.org

❖ IOA's 12th World Congress:

On August 7th through the 12th, 2007, The International Ostomy Association will be holding its **12th World Congress** at the Fajardo Inn, in Fajardo, Puerto Rico. UOAA will be represented by *Kristin Knipp, Bob Baker, Sherry Lessard, Linda and I*, and ... how about you? This is a great opportunity to interact with ostomates from different countries and cultures. IOA's President, Di Bracken, extends a warm welcome to one and all.

For **details about the Congress** check out the following page of IOA's website:
www.ostomyinternational.org/12congress2007.htm

For **details about the hotel** go to the following website: www.fajardoinn.com

And for a **registration form**, click on:
www.ostomyinternational.org/Forms/2007CongressRegistration.pdf

UOAA'S MANAGEMENT BOARD: Up Close and Personal:

Introducing LeeAnn Barcus.....

"I would like to take a moment to introduce myself. My name is LeeAnn Barcus. I have an ileostomy due to Crohn's disease. I am a wife and mother of two, a son and a daughter. I have a license in nursing and have a great passion for helping others. I am on the Board of Directors for my local support group and have been for two years now. I live in the St. Louis area. I am an advocacy volunteer, representing the State of Missouri, as well as all ostomates and people with medical issues.



My passion is to get the word *ostomy* out of the closet. I want to make it an acceptable thing to have and not a feared thing or something one should feel they need to be ashamed of. I would like to see that the products are more easily supplied to all those out there. Insurability for those with issues and ostomies is a great concern of mine. I would like to see it available to everyone and not cause a financial burden.

The group of people with the UOA, and now the UOAA are a tremendously important part of my life. I would not be where I am today without the kindness, caring, and support given by these wonderful groups of people. I hope to give back some of what was given so freely to me. I am available to answer questions, feel free to email me. If I can be of help, in any way, I will do my best to provide that." LeeAnn@uoaa.org

And, Steve Strizic

"I was first diagnosed with ulcerative colitis when I was 17 years old. I finally had my ileostomy surgery when I was 40 years old (1990). I got involved with my local UOA chapter and was elected chapter president the next year. I was invited to join the American Cancer Society Unit Patient Services Committee and the Relay for Life planning committee. I was appointed to the CCFA regional Board of Directors in 1999 and served there four years as their Patient Education chair.



I participated in four regional conferences the first 4 years after my surgery and helped plan two of those. I was asked to join the UOA Field Services Program as Washington State rep in 1996 and was elected to the UOA national Board of Directors in 1997 and served 5 years. I continued in the Field Services Program up until the end of the UOA.

I was an avid weight lifter up till my surgery and spent most of my spare time on the golf course.

I have lived in the Puget Sound area of Washington State all my life and have worked in the Wholesale Optical Laboratory business for over 30 years. I continue to volunteer for the newly formed UOAA as one of their Directors." steves@uoaa.org

❖ **IN CONCLUSION** ... As I wrote this UPDATE I kept thinking, "Wow, this is going to be one heck of a year!" Conferences, both National and International, new ASG-oriented programs coming on line, Leadership Workshops, GYGIG rides, work on the website, Award recipients to be recognized, the IRS to play tag with, and who knows, in the very near future we may learn about the disposition of assets remaining after UOA's dissolution. Your new Management Board of Directors is going to do its very best to show you what a great value affiliation with UOAA is!

With warmest wishes,

Ken Aukett - President, UOAA