



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.

AUGUST 29. 2007

CONFERENCE HIGHLIGHTS

August 15th to the 18th

Lincolnshire Marriott Resort

Suburban Chicago

Check out some photos on

http://www.uoaa.org/files/events/conference_2007_photos.pdf

- 502 people joined us for this inaugural event. This included our special children who brought their parents, lots of young adults, in addition to leaders from at least 75 affiliated support groups, and many more. Close to half of the attendees told us this was their first-ever ostomy conference. The 502 number does not include those who represented their companies in the Exhibit Hall, where 18 commercial and 15 non-profit booths brought the latest information about products and services to the attendees.
- On Wednesday afternoon, the first ever UOAA Golf Outing took place on the Marriott's PGA Championship course. It was a rainy afternoon, but some intrepid golfers did finish the course.
- Wednesday evening, we were greeted by the Hollister staff who hosted everyone at a cook"in", thanks to the rain, complete with, musical entertainment and facility tours at their nearby corporate headquarters. Al Maslov, a man whose support of UOA, IOA and UOAA over the years was greatly appreciated, was honored on the eve of his retirement.
- Thursday morning's Grand Opening featured two presenters:
 - Illinois State Representative Kathy Ryg, who provided the background to "Ally's Law", the Bathroom Access Act and then introduced Ally and her mother in the audience;
 - Paula Erwin-Toth, RN, MSN, CWOCN, who introduced us to a number of important "A" words in keeping with the theme "What a Difference an 'A' Makes".
- Thursday afternoon and Friday morning the Exhibit Hall showcased the latest in ostomy pouching systems, accessories, and their suppliers, as well as a number of related non-profit organizations.
- Thursday evening ConvaTec sponsored their traditional themed evening for all, with a buffet dinner dance band featuring "Chicago Jazz" music.
- The Colossal Colon®, a project of [The Colon Club](#), was on site for viewing. Throughout its time with us, numerous people explored this replica of the large intestine and learned more about the functions and possible mal-functions that can occur.
- Friday morning brought sunshine and about 60 walkers and runners to the Nu-Hope Fun Run, for a tour of the hotel grounds or a walk/bike/run path through the Greenway.
- During Friday's Recognition Luncheon, honors were given to four very special ASG leaders, to the WOCN Nurse of the Year (Linda Reynolds, RN, BSN, CWOCN of Chico, CA), to our Legal Counsel Sheldon Sokol who guided us through the incorporation and IRS legal entanglements, and to the FOW-USA Outstanding Volunteer (the late Mario Pardo). We then

shared in laughter as Brenda Elsagher helped us see the many sides of her father's advice to "Work Hard and Smile Pretty".

- Friday afternoon and all day Saturday, a cadre of excellent presenters conducted workshops on a wide range of topics.
- Friday evening found those interested in adding their thoughts about IBD, with needles or fabric markers in hand, under the guidance of the [IBD Quilt](#) folks.
- Saturday afternoon, at the Closing, we met Craig Wilson, also known as "Farang Ba" – the Crazy Foreigner – subject of a movie of that title about his amateur boxing career in Thailand (one that he has continued to pursue even since his ileostomy surgery).
- Saturday's Closing Banquet featured dinner, comedy and a DJ for dancing – and NO speeches or awards!

Our Thanks Go To Conference Planning Committee And To The Many Volunteers Who Helped Make This Inaugural Conference Such a Success.

Kristin Knipp, Conference Chair
Dave Rudzin, Coordinator of Special Events
Ian Settlemire, Exhibit Hall Manager
Mary Jane Wolfe and her band of ETs who staffed the Stoma Clinic

Jane Michnik & Ginnie Kasten, Local Volunteer Coordinators

Bret Cromer, Hospitality Chair

And many, many more who helped at registration, unloaded and set up CoCo, greeted attendees in the Hospitality Room, stuffed goodie-bags, manned the Speaker-Ready-Room, made presentations or moderated panels, carried messages, and in general were the glue that held it all together so that everyone could benefit from the experience.

And a special note of thanks to our Office Administrator, Joan McGorry, and her husband Pete, who processed the 502 "off" and "on" site registrations and our sleeping room adventure!

501(c)(3) GROUP CHARITY STATUS

We are extending an open invitation to all ASGs that: 1) do not have their own 501(C)(3) Charity Status; 2) were not one of the 28 ASGs covered by the July 2007 IRS letter; and, 3) would like to be in UOAA's 501(C)(3) Group Charity Status, to advise Joan McGorry, by e-mail at oa@uoaa.org, that you want to come under UOAA's Group umbrella. **We need to know of your intent no later than September 21, 2007.** When we receive your e-mail, we will let you know what amendments you need to make to your Bylaws so that they meet the IRS regulations, and how to get your own EIN (Federal Employer Identification Number) if you do not already have one.

Note: As an affiliated group of UOAA you automatically have non-profit status! Having the 501(c)(3) IRS Charity Status allows people or corporations who make a contribution to your ASG to deduct it from their income tax (that is all it does).

ATTENTION ASG LEADERS

Has the number of members in your group changed? If it has, we need to know before September 15th.

The number of votes that your support group has in this Fall's election, and the Annual Affiliation Fee that your group is assessed, is based on the number of members you have. You have one vote for each member. Groups that have reported "no members" will receive 12 votes.

Your AAF is determined by multiplying the number of members that you have reported by the rate established by the UOAA MBoD. Last year this rate was \$ 2.00/member. The rate for 2008 will be determined by the MBoD at its meeting in Skillman, New Jersey, October 25th and 26th. Groups that report "no members" will be assessed a fixed fee. The fixed fee currently in effect is \$ 25.00. You will be advised of any changes in these fees immediately after the October meeting.

❑ **ASG LEADERSHIP AWARDS**

It was indeed a pleasure at the Conference Recognition Luncheon to have the opportunity to put the UOAA spotlight on a group of volunteer Affiliated Support Group Leaders that have been doing an outstanding job in furthering the mission of UOAA and the cause of ostomy surgery rehabilitation in their local community.

This past Spring the UOAA affiliated support groups were asked to nominate a person in their group, a volunteer leader, that they believed was doing an outstanding job.

The Award Criteria included a statement regarding their candidate's

- ❑ Affiliated Support Group experience, past (UOA) and present (UOAA);
- ❑ A listing of accomplishments at the Support Group level; and,
- ❑ A description of why their ASG was a better organization because of their nominee.

The Award Selection Committee was Chaired by Charlie Grotevant. In addition to a plaque each recipient received a check for \$ 500 to help pay for the expenses associated with attending the conference. The next awards will be made at the 2009 Conference in New Orleans.

The Award recipients for 2007 are:

- **EILEEN C. BOHRER**
nominated by the ST. PAUL OSTOMY ASSOCIATION
- **DEMI COTRUPE**
nominated by the **OSTOMY SUPPORT GROUP** of NORTH SAN DIEGO COUNTY, INC
- **HARVEY SHATZ**
nominated by the OSTOMY ASSOCIATION OF SOUTHERN N.J.
- **MARY LOU THOMAS**
nominated by the ANNE ARUNDEL COUNTY, MARYLAND OSTOMY ASSOCIATION, INC.

Congratulations are extended to all leaders who were nominated! Your work, ostomates helping ostomates, is greatly appreciated.

❑ **WOC NURSE OF THE YEAR AWARD**

It was at the Recognition Luncheon where I had the chance to acknowledge the dedicated service of one of our medical Community's finest nursing professionals. An ostomy patient support group that has a committed WOC Nurse as an active participant in their rehabilitation activities is indeed most fortunate. A most valuable resource who can serve as a teacher, a healer, a motivator, a facilitator, as well as an enabler and mentor ... a person who can put life into a visiting program and dramatically impact an ostomy patient's quality of life potential.

Of the many excellent nominations that were received, our Award Selection Committee, Chaired by Jan Clark, felt that the rationale presented by The Ostomy Association of Greater Chico California for their candidate, was worthy of the highest recognition.

Accordingly, UOAA's first WOC Nurse of the Year Award was presented to a medical professional who calls herself an ET, who serves a group that calls her wonderful, Chico's own,

Linda Reynolds, RN, BSN, ET, CWOCN

❑ **UOAA SPECIAL RECOGNITION**

Sheldon Sokol, Esq. is a person whose actions on behalf of UOAA merit special recognition. He is a person with whom I discussed my ideas about the formation of a new national ostomy association and whose advice and counsel I both respected and followed – most of the time. Sheldon took the initiative and applied for UOAA's EIN. He then filed for UOAA articles of incorporation in New Jersey and it was his application to the IRS that resulted in UOAA obtaining its 501(c)3 charity status. When I spoke to him about my desire to file with the IRS for a group charity status classification for any affiliated support group that met the IRS

requirements, he rolled his eyes and said “Ken ... this is going to take time, patience, lots of paper, and maybe, just maybe, if we are lucky, we will get approval ... the IRS does not like to grant these group applications. And truer words were never spoken! It took 13 months and 5 re-submissions but last month, we received our group status. I would be remiss if I did not mention that all of his work has been pro-bono.

❑ **CODE OF CONDUCT FOR WEBSITE DISCUSSION BOARD POSTERS**

Attached for your information is a copy of the [Code of Conduct](#) that the UOAA MBoD has approved for the guidance of posters on UOAA's Discussion Boards.

❑ **GYGIG PRESENTATION**

Of special note at the Conference's Closing Session was a presentation made to UOAA by Judy Pacitti, Ride Director of [Get Your Guts in Gear](#). 3 rides were held in 2007, the first in the Austin, Texas area, the 2nd in the New York Catskills and the 3rd in the beautiful Northwest Washington region. These rides are undertaken to promote awareness about IBD and the consequences of these diseases, such as “ostomy surgery” and to raise funds for beneficiary organizations such as the IBD Quilt Project, the Colon Club, CCFA and UOAA. This year UOAA had participants in all 3 rides, most notably our senior statesman, Charlie Grotevant, Bob Baker and his son, Julielyn Gibbons, Emily Mallar, Paul Warning and Ian Settlemire with crew members including Kristin Knipp, Joyce Grotevant, George Salamy and Steve Strizic. Judy received a great ovation when she presented us with a check for \$ 42,000 - with the statement that there might be a few more dollars when the accounting process is complete. **Start your training now** for the rides that will take place in 2008. You can do it ... if you have your doubts, just give Brenda Elsagher a call ... she completed 200 of the 210 miles in 2006 on a recumbent bike, with two knees that should have had surgery even before the ride!!

❑ **IOA 12TH WORLD CONGRESS IN FAJARDO, PUERTO RICO**

One week before our UOAA Conference, Kristin Knipp, Bob Baker, Linda and I traveled to the Fajardo Inn in the northwest of Puerto Rico, as UOAA's delegates at the IOA 12th World Congress ... “Viva Life – Viva La Vida”.

Before the IOA World Council convened our Region, the North and Central America and Caribbean Ostomy Association, or NCACOA held its House of Delegates meeting. At the election of officers, Linda assumed the office of Immediate Past President with Doug Graham of Canada elected as President. George Salamy was elected as Vice President and Jorge Vargas from Colima, Mexico was elected Member at Large. UOACanada will take on the responsibilities of Treasurer. There will be a Regional Conference in Colima, Mexico probably in February 2009.

As a result of this meeting, the Ostomy Association of Trinidad/Tobago submitted an affiliation application to me and subsequently has become our 249th ASG.

At the IOA election, Di Bracken from Toronto, Canada assumed the office of Immediate Past President with the election of Vladimir Kleinwachter from the Czech Republic as President. Dr. Harikesh Buch from India was elected Vice President. Gene Zapf from Edmonton, Canada will stay on as Treasurer with Ann Favreau, from Venice, Florida serving as Secretary.

The big news from this Congress is that it will be the last full IOA Congress. In the future the IOA will hold its World Council Meetings at locations to be determined by the Executive Council. This could be in conjunction with Regional Conferences. Lack of attendance at the most recent Congresses and diminishing corporate sponsorship support were listed as the key reasons for this decision. There were only 127 attendees at the Fajardo Congress.

As the most recent recipient, I had the honor to present the Archie Vinitzky Award to a most distinguished humanitarian and champion of ostomy rehabilitation, John O'Neill from Wanganui, New Zealand.

Linda and I were asked to present a workshop on "Intimacy Concerns of People with an Ostomy". We tailored a PowerPoint presentation that had been given at a WOCN Regional Meeting, and last year to an International Symposium on Stoma Rehabilitation in Guangzhou, China. If you would like a copy of this presentation to use at a monthly meeting or as an in-service to home health care nurses, email me at kenaukett@uoaa.org.

changed, that a duct or tube naturally created has been replaced by a new, human creation. Physically this change is observable. Yet, it also lies within the recesses of our emotional center. Different, yet still creatures of God, we embrace life with a new-found gratitude. The simple words of prayer are significant for us. Our gratitude turns to those who have become God's partners in creation, who have created new ducts and tubes that sustain us in life. Today we gather in support of one another working to see ourselves and to help others to see us not as damaged, not less than a perfect creation, but as a gift; as wondrous, vital forces of life different only in the bravery we have had to adopt, the courage we have had to embrace, and the forgiveness we have had to extend.

"O God, let all here be strengthened in their daily lives. May we see ourselves as miraculous and as normal. May You give us the determination to work toward bringing comfort and understanding. Instill in us a sense that we are still a perfect creation. Bless those who care for us, guide them. Open the hearts of those different from us. Help them to see not a small, yet significant change, but the whole of us. L'chaim – to life!"

□ ASG LEADERSHIP SEMINARS

SAVE THESE DATES

- On October 27th an all day ASG Leadership Seminar will be held in the ACS Office on Route 1 in North Brunswick, New Jersey. This meeting is sponsored by an Educational Grant from ConvaTec.
- On November 17th an all day ASG Leadership Seminar will be held in the Crowne Plaza Hotel in Irvine, California. This event is sponsored by an Educational Grant from Coloplast.

Look for more details from UOAA's Leadership Resource Program Chairman, Steve Strizic in the near future.

□ LUNCHEON BLESSING

The following is the text of the prayer that Rabbi Looper gave at the Recognition Luncheon at our conference. Its message is so meaningful that it must be shared with you:

"Embedded in the morning liturgy that a traditional Jew recites is a prayer that praises God for creating within us a system of ducts and tubes. The prayer acknowledges that if one of these were to be closed it would not be possible to exist. Gathered here today we recognize that our bodies have been

□ IN CONCLUSION

Well the summer of 2007 has certainly been an eventful period for UOAA. As Fall approaches I see more challenges on the horizon and more opportunities for successful ventures. Your MBoD will continue to work for you, and I trust that you will support our initiatives for the betterment of all ostomates.

Take a well deserved rest this Labor Day weekend, sit back and smell the roses you worked so hard to nurture and cultivate.

Ken Aukett
UOAA President