



*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.*

**JULY, 2008**

## **WOC NURSE OF THE YEAR RECIPIENT**

It was again an honor to have the opportunity to present UOAA's WOC Nurse of the Year Award for 2008 at the WOCN Society's Annual Conference which was held this year in Orlando. The candidates that you nominated were evaluated by an Award Selection Committee consisting of Jan Clark, Chair, and Committee members Stanley Cooper, LeAnna Geurin, Marilyn Mau, last year's recipient Linda Reynolds and Jim Rice.



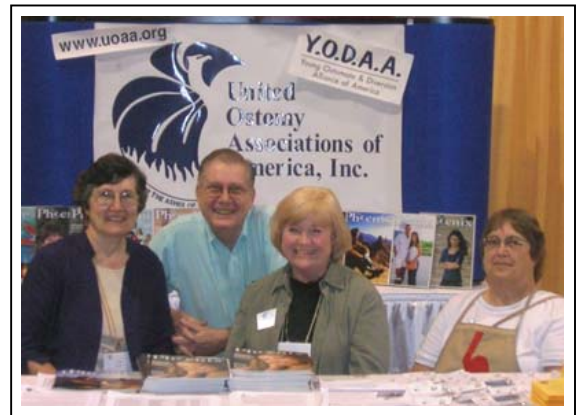
Consideration was given to each candidate's contribution to their support group's viability, including governance, educational programming, participation in group projects such as its visiting program, fund raising, public awareness and outreach, assistance in editing and distributing informative newsletters, and the provision of one-on-one counseling regarding ostomy management problems.

Due to the excellent qualifications of the candidates you nominated the selection process was difficult but in the end the Committee judged that the rationale submitted by the Ostomy Support Group of Crouse Hospital located in Syracuse, New York, was worthy of our highest recognition.

Described by her nominator, this year's recipient is passionate about ostomy care. A dedicated attendee of every support group meeting, she mixes education with humor and compassion, caring for the needs of "old timers" as well as those of those whose stomas are still shrinking. People may enter the meeting room with concerns and doubts, but they leave with a feeling of empowerment and the ability to cope with their new plumbing.

The 2008 UOAA WOC Nurse of the Year Award was presented to **Heidi Cross**, RN, MSN, FNP-BC, CWOCN, Wound & Ostomy Nurse Practitioner. (Shown in the picture to the left, I am presenting the Award plaque to Heidi.)

## **WOCN SOCIETY CONFERENCE**



As evidenced by the smiling faces above (from right to left, Eileen Bohrer, Joan McGorry, Ken Aukett and Linda Aukett) our three days of exhibiting at the WOCN Society's Annual Conference in Orlando, celebrating 40 years of "Nursing Excellence", were most productive. Interest was very high about how to start support groups in a hospital environment and how to subscribe to **The Phoenix** magazine. Our thanks to the WOCN Society and its President Jan Colwell for giving us a comp booth in a location directly across from a food station that guaranteed an excellent flow of attendees past our booth.

## **THEMED PHOENIX PATIENT RESOURCE MAGAZINES**

Within the next several weeks you will be receiving sample copies of the first two **Phoenix Patient Resource magazines** ... one dedicated to Colostomy patients and the other to Ileostomy patients. The magazines targeted for Urostomy and Continent Diversion patients will be distributed later this summer.

These magazines are for use in your group's Visiting Program as an adjunct to the material that makes up the "Visitor Information Packet" ... packets that you either give directly to visited patients or mail to them. They can also be given to new post-op patients attending their first support meeting. (They are not intended for widespread distribution to your membership or rehabilitated patients.)

These magazines represent a "UOAA project in progress". Articles and advertisements in future production runs may be changed as deemed appropriate by the UOAA Editorial Board. Initially there will be no charge for these magazines. It is hoped that a sponsor or educational foundation may be identified to underwrite the associated expenses allowing UOAA to continue to provide these to their affiliated support groups as a service. While supplies last, if you want to receive additional copies, e-mail Joan McGorry at the UOAA office. Because the quantities are limited orders may not exceed six copies of any one themed magazine per order, and, there needs to be a minimum of 2 months between repeat orders. There will be a \$ 5.00 charge per order to cover shipping expenses.

Your comments regarding these magazines will be appreciated. Please e-mail them directly to Joan.

## ADVOCACY NEWS

### GOOD MEDICARE NEWS:

#### PLEASE PASS THIS ON TO YOUR MEMBERS:

Despite efforts by UOAA and the entire home medical equipment industry to stop it, July 1 marked the beginning of a Medicare program known as "**Competitive Acquisition**" or "**competitive bidding**" (CB). This program – starting this year in only 10 major metropolitan areas - was authorized by Congress at the same time they set up the Medicare prescription drug program. It is intended to lower the amount that Medicare pays for selected medical supplies and equipment, to partially pay for the prescription program.

**The GOOD NEWS is that NONE of this affects ostomy supplies.** A person who is receiving their supplies through Medicare, regardless of where they live, can continue to get their ostomy supplies at the dealer they have been using, if they wish to do so. A situation that might change that would be if their present dealer is in one of the 10 CB areas and

decides to get out of the ostomy business because of some other impact of the CB program.

The 10 "Round one" competitive bidding areas are:  
Charlotte-Gastonia-Concord, NC-SC  
Cincinnati-Middletown, OH-KY-IN ... Orlando, FL  
Cleveland-Elyria-Mentor, OH ... Kansas City, MO-KS  
Dallas-Fort Worth-Arlington, TX ... Pittsburgh, PA  
Miami-Fort Lauderdale-Miami Beach, FL  
Riverside-San Bernardino-Ontario, CA  
San Juan-Caguas-Guaynabo, PR

### MORE GOOD ADVOCACY NEWS FROM OHIO:

Remember ***The Phoenix*** article about **Ally** – the young woman who was instrumental in getting a bathroom access law passed in the state of Illinois? She has not rested on her laurels, and is working with folks in several other states on passage of similar laws. We are happy to announce that the Governor of Ohio, Ted Strickland, has recently signed a bill that was passed by the **Ohio legislature, the IBD Restroom Act.** At the moment, this kind of legislation has to pass state by state. If you are interested in helping in your State, please let us know.

## GREAT COMEBACKS AWARDS

As I reported in my March 2008 UPDATE, UOAA was invited to become a sponsor of the Great Comebacks<sup>®</sup> Program, joining long-time program sponsors ConvaTec, the Crohn's & Colitis Foundation (CCFA) and Rob Hill's Intestinal Disease Education and Awareness Society (IDEAS\*) that provides information to children about intestinal diseases.

Now in its 24th year, the Great Comebacks<sup>®</sup> Program annually recognizes people who have fought courageous battles against Crohn's Disease, ulcerative colitis, or who have undergone ostomy surgery. Since 1984, the men and women who have received this Award have served as role models to thousands of people across America.

Recent recipients who are associated with UOAA include our current Vice President, Bob Baker; Director, Charlie Grotevant; Teen Network Chair, Jude Ebbinghaus; Broward Ostomy Association President Wendy Lueder; and, Abby Ryan who received an Ina Brudnik Scholarship Award for those of college-age.

I'm delighted to share that the program is looking to add new faces to the Great Comebacks<sup>®</sup> family, but ...

**URGENT NOTE** ... the deadline is fast approaching

for this year's award process. If you would like to share your story of hope and giving, or you know someone who would like to share their story, I encourage you to visit [www.GreatComebacks.com](http://www.GreatComebacks.com) and submit a nomination for yourself or others by **July 15, 2008**. Eligible entries received after July 15, 2008 will be considered as part of the 2009 process.

And to those who feel that they are not "special", please read the following message from this year's recipient, Scott Ellis:

"Diagnosed with ulcerative colitis at age 9, I was determined that my disease wouldn't stop me from following my dream of becoming a firefighter. I fulfilled that dream and want to show others that surgery can be a beginning rather than an end. That's really why I entered the Great Comebacks Program. I lead a full life and want to help others push through their hardships, knowing there is a community of support cheering them on. You don't have to accomplish some great feat or heroic task to enter. I was originally hesitant to apply because I didn't think I deserved an award, but my wife Marla helped me realize that each of our stories is important and Great Comebacks is about reaching out and encouraging each other. If you would like to share your story of hope and giving, or you know someone who would like to share their story, I encourage you to visit [www.GreatComebacks.com](http://www.GreatComebacks.com) and submit a nomination for yourself or others. Good luck, and maybe I will be welcoming you into the Great Comebacks family this fall!"

## **Pull-thru Network's 20<sup>th</sup> Anniversary National Conference**

Participate in an historic event! Twenty years have transpired since that first group of parents met with each other to share information about their child's congenital colorectal, anorectal or urogenital disorder. In that time this mutual aid initiative has expanded to the point where, today, the now well organized Pull-thru Network, governed by a dedicated Board of Directors, is undertaking its largest project, committing significant financial and manpower resources to convene this celebration of caring, hope and life.

PTN, an affiliated support group of UOAA stands alone as our nation's most comprehensive source of information, education, assistance, and advocacy to, and for that special community it serves.

PTN's 1<sup>st</sup> National Conference, will take place on **July 24 – 27, 2008** at the Doubletree Hotel and Conference Center, 16625 Swingley Ridge Road, **St. Louis/Chesterfield, Missouri**. Call 636-532-5000 for reservations. PTN's special rate is \$ 97/night + taxes.

## **GYGIG 2008 RIDE SCHEDULE**

### **It's More Than a Ride! Join "Get Your Guts in Gear" in 2008"**

It's time to gear up for the ride of your life! [Join Get Your Guts in Gear](#) for its 3rd annual Pacific Northwest Ride for Crohn's and colitis, August 1st - 3rd. Register now to ride this scenic route over Whidbey Island viewing the Olympic mountains, the rolling hills of Skagit county, and the beautiful back roads of Snohomish county. You can also join GYGIG this fall from October 17-19 to experience the scenery of Central Texas.

Whether you are an experienced cyclist looking for a great ride or a novice rider who is affected by one of these diseases, you'll enjoy GYGIG's scenic, fully supported rides. Don't ride a bike? Become a part of the GYGIG community by joining the all-volunteer crew, which is an integral part of each Ride.

Every pedal stroke of the ride is an empowering experience, riding for those who can't and bringing together those affected by the disease or surgery for something positive. Add your strength to the 1.4 million Americans in the Crohn's and colitis community and the 600,000 ostomates while raising funds, awareness, and spirits in the fight against Crohn's disease, ulcerative colitis and ostomy surgery.



Each of the Rides created and produced by Get Your Guts in Gear, Inc. ("GYGIG") is an opportunity to connect with patients, family, and friends who are affected by Crohn's disease and ulcerative colitis.

### **Seattle Area Route - August 1-3, 2008**

Scenic loop that includes Whidbey Island & the Skagit Valley.

## Texas Route - October 17-19, 2008

Starts from LaGrange and ends near Austin, winding through the Lost Pines, the Guadalupe River, and the Hill Country.

Each GYGIG Ride spans three days, and averages 70 miles per day. The Rides are fully-supported and include two overnight camping stops to relax and recharge your engines with food, friends, hot showers, and even towel service. All of GYGIG's Rides include an opening ceremony on day one and a closing ceremony on day three to celebrate the efforts and dedication of every rider and crew member.

For more information and answers to FAQs, please visit [www.IBDride.org](http://www.IBDride.org). Want to talk to someone about how you can get involved? Call GYGIG at 866.9IGOTGUTS (866-944-6848). Don't miss this opportunity to join GYGIG this year!



## YODAA CONFERENCE

### "YODAA ROCKS IN CLEVELAND"

The Young Ostomy and Diversion Alliance of America, an affiliated support group of UOAA for those between the ages of 18 and 35, is holding its 2<sup>nd</sup> national conference on **August 9–13, 2008** in the **Hilton Garden Inn** (located in downtown Cleveland), 1100 Carnegie Avenue, Cleveland, Ohio. The conference rate is \$ 115/single & 125/double + taxes. Call 216-658-6400 for a hotel reservation.

Want more information about this event? Visit [www.yodaa.org](http://www.yodaa.org).

## NORTHWEST REGIONAL CONFERENCE

A Northwest Regional Conference will be at the **SEA-TAC Airport Clarion Hotel**; 3000 S. 176<sup>th</sup> Street, **Seattle**, Washington on **September 12<sup>th</sup> to the 14<sup>th</sup>**. Hotel room rate is \$ 79.99/night + taxes. Call 206-242-0200 to make a room reservation.

To make a conference registration for this Northwest Regional event please contact Janet McNiven. The registration fee of \$ 55. Includes a continental breakfast and buffet lunch.

Conference events include a social mixer sponsored by Coloplast on Friday evening, educational programming on Saturday and a Leadership session on Sunday morning.

For additional information about this event contact Steve Strizic.

## MID ATLANTIC REGIONAL CONFERENCE

The Delaware Valley Regional Taskforce, a consortium of UOAA ASGs in the Eastern Pennsylvania, Southern New Jersey, Delaware area, will convene a Regional Conference on **November 21<sup>st</sup>** through Sunday morning, the **23<sup>rd</sup>** at the **Holiday Inn in Cherry Hill, New Jersey** (15 minutes from downtown Philadelphia).

The keynote speaker for the Saturday educational program will be **Scott Ellis**, Great Comeback Awardee for 2007. The day will include workshops of interest to all ostomates and those with continent diversions, a product exhibition, and a free Stoma Clinic staffed by local WOC Nurses. The evenings banquet will feature entertainment by comedian, author, and ostomate **Brenda Elsagher** ... an evening with Brenda is a must!

Mark the **November 21-23** dates on your calendars now. More detailed information will be distributed in the near future.

## NEW ORLEANS CONFERENCE PLANNING MEETING

A 2009 National Conference planning meeting, followed by a UOAA Management Board of Directors Meeting will be held at the New Orleans Sheraton Hotel on August 21<sup>st</sup> through the 23<sup>rd</sup>.

It is not too early to start planning to attend **UOAA's 2<sup>nd</sup> National Conference on August 5<sup>th</sup> through the 8<sup>th</sup>, 2009**. Of special note, an invitation has been extended, and accepted by the International Ostomy Association's **20/40 Focus** to participate in this event at they celebrate their 10<sup>th</sup> Anniversary. Young ostomates from around the world will be meeting with the UOAA's YODAA affiliate in what should prove to be a most exciting event. The sharing of information and global networking make this a "must attend" gathering.

## **OSTO-GROUP – APPLIANCES FOR THE UNINSURED**

Osto-Group, the non-profit organization that provides donated ostomy supplies to uninsured ostomates in the United States for the cost of shipping and handling, is **under new management**.

Stephanie Sullivan, herself an ostomate and President of Wholeness House, a ministry to women and women with children who have experienced crisis in their lives, viewed the acquisition of Osto-Group as an opportunity to serve both the ostomy community and as a hands-on business training experience for the women of Wholeness House.

For more information about Osto-Group visit [www.ostogroup.org](http://www.ostogroup.org) or about Wholeness House visit [www.wholenesshouse.org](http://www.wholenesshouse.org)

Ostomy supplies may be donated to Osto-Group by sending them to:

Stephanie S. Sullivan,  
Osto Group  
5773 Golden Eagle Circle  
Palm Beach Gardens, FL 33418-1518  
877-678-6690

IRS tax deduction receipts will be provided for all contributions. Please note that “partial boxes” of supplies, wipes and “urostomy appliances” will be accepted.

## **WORLD OSTOMY DAY 2009 OBSERVANCE**

Based upon information received from IOA I announced that **World Ostomy Day, 2009**, would be observed on **Saturday, October 3<sup>rd</sup>, 2009**. Shortly thereafter I received a letter from Beth Meltzer-Abelow, President of the Ostomy Association of Boston, advising that the October 3<sup>rd</sup>, 2009 date selected for this world-wide observance conflicted with two fairly major Jewish Holidays .. Sukkot and Shmini Atzeret & Simchas Torah. Beth requested that consideration be given to moving the World Ostomy Day observance to **October 17<sup>th</sup>, 2009**.

I brought this information to the attention of the IOA Executive and recently received the following letter from acting IOA President Di Bracken.

*“Dear Ken,*

*At our IOA Executive meeting held in Ljubljana, Slovenia, information and plans regarding the 6<sup>th</sup>. World Ostomy Day were presented by Peter McQueen, Coordinator of WOD.*

*The decision was made by the members of the Executive Council to uphold the tradition of holding World Ostomy Day on the first Saturday of October; in this case 3 October 2009.*

*We understand that there are religious celebrations taking place on this date but this was the case in 2006 when there was conflict with the date in some countries in the Asian region. There were also clashes in Brazil with the date but in both areas, World Ostomy Day celebrations were carried out after the set date.*

*The Executive Council decided to uphold the World Ostomy Day date of October 3, 2009 with the understanding that the activities may be planned before or after the set date due to many circumstances. Look for further information from Peter McQueen in regard to the activities that are scheduled to take place.*

*Ken, I would appreciate it if you share this information with other interested parties who may be in contact with UOAA.*

*With Best Wishes*

*Dí*

*Dielwen Bracken, Acting President.*

Based upon this response it is my intent to bring this matter to the attention of the UOAA MBoD when we meet next month in New Orleans. I will propose that observance in the United States be moved to October 17<sup>th</sup>, 2009. I would appreciate hearing from you if you have any information that you would like me to share with the MBoD members when they deliberate this proposed change.

## **IN CONCLUSION**

It is surprising when you sit down at your computer and start to write an UPDATE such as this you wonder, now what the heck do I want to say .... and then five pages later you think again, “wow, UOAA is one busy place” ... and there are four projects in the works that I am saving for the next UPDATE to comment on.

This is a special time of the year for all Americans and I hope that you have a few moments over the next several days when you can reflect on the freedoms that we have and the struggles that we have faced and will face to retain them ... United we can accomplish great things. Be well.

*Ken Aukett - President, UOAA*