



*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. 2009

### ❑ ASG ADVISORY BOARD APPOINTMENTS

I am pleased to announce that the Management Board of Directors at its January meeting approved the appointment of the following three people to the ASG Advisory Board. They will serve until December 31, 2010.

- ✓ **Katie Torango**, Salem Township Hospital, Illinois
- ✓ **Pat Parish**, Hemet-San Jacinto Ostomy Association, California
- ✓ **Tillie Horak**, Baltimore Ostomy Association, Maryland

**Demi Cotrupe**, Ostomy Support Group of North San Diego County will Chair the ASG Advisory Board.

### ❑ 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?

Now is the time for you to submit nominees for the **2009 WOC (ET) Nurse of the Year Award**. This award will be presented to the recipient at the WOCN Conference, June 7<sup>th</sup>, 2009 in St Louis, in the presence of their peers, and again at the UOAA National Conference in New Orleans at the Recognition Luncheon on August 7<sup>th</sup>. 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.

**Attached to this UPDATE is a Nomination Form. Nominations must be received no later than APRIL 15<sup>TH</sup>, 2009.** Submit the form to **Jan Clark**, Award Selection Committee Chair, by e-mail: [janclark@sbcglobal.net](mailto:janclark@sbcglobal.net); or 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 **2009 ASG Leadership Award**. Four (4) awards will be presented to those nominees determined by the Award Selection Committee to be most deserving. Attempts will be made to spread the awards around the country. These Awards will be presented at the New Orleans Conference Recognition Luncheon, on August 7. Each Award recipient will receive a complimentary conference registration, a Luncheon ticket and partial reimbursement of their travel expenses.

Each Award recipient will be invited to serve as a member of UOAA's ASG Leadership Advisory Board for a 2 year term commencing January 1<sup>st</sup>, 2010.

**Attached to this UPDATE is a Nomination Form. Nominations must be received no later than MAY 1<sup>st</sup>, 2009.** Forms may be e-mailed to Joan McGorry at [oa@uoaa.org](mailto:oa@uoaa.org), mailed to her at P.O. Box 66, Fairview, TN, 37062, or Faxed to: 615-799-5915

### ❑ RACE CAR DRIVERS PROMOTE COLON CANCER AWARENESS AT DAYTONA EVENT

See attached article for details about this Blue Star race.

### ❑ CONSTITUTION AMENDMENTS

If you have not done so already, please review the Constitution Amendments that were previously sent to you for approval ... changing the length of term of the President, President-Elect and Vice President from 3 year terms to 2 year terms. All votes must be received by Joan McGorry by February 28<sup>th</sup>. Ballots can be e-mailed to Joan at [oa@uoaa.org](mailto:oa@uoaa.org).

### ❑ C.A.R.E.S. PROGRAM

Applicant submission deadline is **MARCH 15<sup>th</sup>, 2009!**

□ **GET YOUR GUTS IN GEAR IN 2009**  
**GOT GUTS? GEAR UP IN 2009!**

You can take a stand for empowerment by taking a seat on a bike or come along and crew the Ride! Join in the fun this year and **seize the opportunity** to connect with patients, family and friends who are affected by Crohn's disease, ulcerative colitis or have an ostomy. You can make a difference and have a blast along the way! Here is what people are saying about GYGIG's Rides:

"GYGIG's events are vastly more than bike rides. Each Ride creates an environment where those from different walks of life who face similar medical adventures can develop profoundly deep friendships. Yet, the atmosphere is so inclusive that all are welcome to share in the special bonds that develop."

- Phil L., rider

"It's been a long time since I truly felt like I was making a difference. Watching my daughter battle Crohn's is so frustrating as I feel helpless in doing something about it. The Ride is the perfect event to empower all of us. It really is more than a ride - I can't wait to do it again - hopefully next time with my daughter riding with me!"

- Margaret M., rider

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 our scenic, fully supported rides.

**WANTED .... RIDERS!!!**

**Three Rides, Three ways to take action!**

□ **New York's Hudson River Valley .....**  
**June 12-14, 2009**

Depart from New York City and head north through the Hudson River Valley, one of the most picturesque settings of the Northeast.

□ **Pacific Northwest / Seattle Area .....**  
**August 7-9, 2009**

Ride north of Seattle, exploring beautiful island coast lines and summer scenes of the rural Skagit Valley, while taking in the vistas of the Cascade Mountains.

□ **Inaugural Ride in the Midwest .....**  
**October 2-4, 2009**

Cycle through the rolling fields of northern Illinois and southern Wisconsin and experience the spectacular Fall colors and lake country views.

Each of GYGIG's Rides averages 70 miles per day, with two overnight camping stops to relax and recharge your engines with food, friends, and a hot shower. All three routes include an opening ceremony on day 1 and a closing ceremony on day 3 to celebrate the efforts and dedication of every rider and crew member.

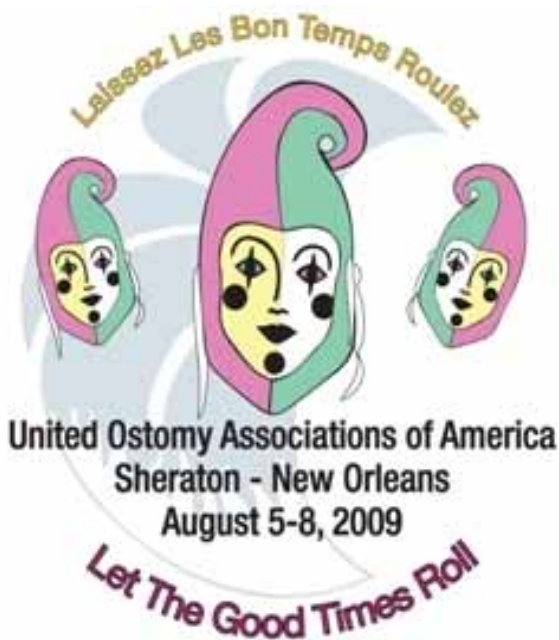
- The events provide opportunities to overcome physical and emotional challenges within a supportive Ride Community. By completing the Ride, many participants find physical strength and emotional resolve they never even knew they had.
- During the Ride, cyclists will be fully supported by the staff and the devoted, all-volunteer Crew. GYGIG provides meals and route support, including fully-stocked rest stops, sweep vehicles, and baggage transport between camps.
- Funds are raised for Get Your Guts in Gear, Inc., the Crohn's & Colitis Foundation of America, The Colon Club, the United Ostomy Associations of America, and Advocacy for Patients with Chronic Illness, Inc. .... organizations that are committed to raising awareness, finding a cure, and ending the suffering caused by Crohn's & colitis.
- Since 2004, GYGIG has returned more than one million dollars in proceeds to support work for empowerment, awareness, and research!
- Riders have consistently raised an average of more than \$2,700 each, with ongoing support and encouragement from GYGIG's experienced staff. Fundraising gives cyclists the chance to both spread awareness and raise vital funds to support the Crohn's and colitis and ostomy communities.

Participants are able to draw strength and support from fellow riders and volunteers, many of whom are touched in some way by Crohn's, colitis or have an ostomy. Wherever the Rides take you, you'll always be surrounded by the solidarity of your peers. Whatever you may need, whether it's a helping hand or maybe just someone to talk to, it's only a few pedal strokes away.

There is an \$85 registration fee for riders and Crew, and each rider needs to raise at least \$1,800 per Ride to participate. For more information, please

contact GYGIG at (718) 875-2123 or e-mail them at [info@ibdride.org](mailto:info@ibdride.org). Riders and crew 18 and over may register online. For information concerning riders, crew ages 12-17, and other FAQs, please visit [www.IBDride.org](http://www.IBDride.org).

## NEWS FROM NEW ORLEANS



We have been working with the Chef at the Sheraton Hotel to come up with some authentic New Orleans food for our two food events!

At Friday's Recognition Luncheon the choices will be:

- ✓ **Grilled Breast of Chicken** with wild mushroom sauce, grilled tomatoes and saffron risotto .... or
- ✓ **Grilled Flank Steak Salad** with peppery greens, roasted onions, sliced tomato
- ✓ With, Trio of Sorbet and Iced Tea

And at Saturday's Closing Banquet the choices will be:

- ✓ **Duo of Grilled Chicken Breast and Gulf Shrimp** with caramelized onion mashed potato, baby vegetables, stone ground mustard sauce...or
- ✓ Pan seared **White Tuna**, potato galette and leeks fondue
- ✓ With a Salad and Dessert consisting of pina colada cheesecake with fresh berries and coconut sauce.

- **UOAA BLOG ... CHECK IT OUT**  
<http://uoaa.wordpress.com/>

### □ YOUR HELP IS REQUESTED

A research team at the University Of Iowa College Of Public Health is looking for survivors of colorectal cancer who can share their stories about a time when a physician's timely recommendation for colorectal cancer screening resulted in the discovery of cancer or pre-cancer. Funded by the Iowa Department of Public Health, the research team is currently working on developing campaign materials for promoting better provider-patient communication about colorectal cancer screening. If you are interested in helping them by sharing your stories, or want to know more about this project, please contact Dr. Yong-Chan Kim at [yong-chan-kim@uiowa.edu](mailto:yong-chan-kim@uiowa.edu) or 319-384-9395.

### □ AND IN YET ANOTHER STUDY

UOAA has been approached by Find-A-Cure-Panel about assisting them in developing a panel with patients / survivors with colon cancer. Find-A-Cure-Panel will donate \$25 per completed survey to UOAA. For those support groups with colon cancer patients interested in participating in this initiative, please contact FACP President, Doug Lowell at [dlowell@sampleczar.com](mailto:dlowell@sampleczar.com) or 323-717-8117.

### □ WORLD OSTOMY DAY ... WOD 2009 SATURDAY, OCTOBER 17<sup>TH</sup>

Start planning your WORLD OSTOMY DAY 2009 activities now, and please let Joan McGorry know what you will be doing so that we can publicize these events worldwide

Traditionally WOD is held on the 1<sup>st</sup> Saturday of October but in 2009, the Ostomy Association of Boston advised that this date conflicts with the widely observed Jewish Holidays of Shmini Atzeret & Simchas Torah. Accordingly, UOAA's MBoD approved moving the official WOD'09 observance in the United States to Saturday, October 17<sup>th</sup>.

### □ DOES YOUR ASG HAVE YOUNG ADULT ACTIVITIES

In an attempt to reach out to those ostomates between the ages of 20 and 35, Eric Eng, co-chair of YODAA ... the Young Ostomate & Diversion Alliance of America, is trying to identify all of the support groups throughout the US that have special programming or services for his youthful community. Once these groups are identified they will receive a special designation on the website and in **The Phoenix** ASG Directory to better assist people who are searching for this type of support.

If your group offers this service, please contact Eric at [eric.eng.anteater@gmail.com](mailto:eric.eng.anteater@gmail.com)

□ **NICE GOING, DUANE**

Congratulations are in order for Duane Ebarb, President of the Shreveport Bossier (Louisiana) Ostomy Support Group, who was the recipient this past December of an Outstanding Leadership in Disabilities Award. Hosted by the Louisiana Governor's Office of Disability Affairs, GOLD Awards were presented to individuals for their outstanding achievements in the disability community. When the Awards were presented by Louisiana's First Lady, she commented, *"Each recipient of the Governor's Outstanding Leadership in Disabilities Award has demonstrated a remarkable commitment to their fellow citizens and to community service. It is Louisianans like these that are working tirelessly each day to improve lives of others, and for that Bobby and I are grateful. Congratulations to each winner – these awards serve to symbolize every life that you have impacted and every life that you will continue to touch."* This Award is presented to a man with disabilities, recognized for his leadership abilities and achievements as a disability advocate. In addition to being President of his Ostomy Support Group Duane is currently the president of the Shreveport Mayor's Advisory Council for Persons with Disabilities and is the Region 7 Louisiana Citizens for Action Now (LaCAN) Leader with the Louisiana Development Disabilities Council.

□ **IN CONCLUSION**

A word of **WARNING !!**

There is a nasty intestinal bug making the rounds ... "norovirus" ... that can be especially harmful to people with ostomies. Take this advice from two who found out the hard way. Even though we both had our regular flu shots, Linda and I both were attacked by this monster ... one minute feeling A-OK, the next hour in the ER. Linda was treated and released but I was confined to a hospital bed for 5 days ... dehydration and electrolyte imbalance caused by severe nausea and diarrhea. This is not something to fool with ... if you have the symptoms -- and there is no mistaking them -- get immediate professional help ... make it known in a loud voice that you have an ostomy and require immediate IV fluid replacement. I spent 4 hours in the ER triage before my system crashed, and what was a relatively simple problem turned into a life-threatening medical emergency!

Please take care, we all have much work yet to do!

***Ken Aukett***

President, UOAA