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## UOAA - ' A NEW BEGINNING '

### **What is UOAA?**

The United Ostomy Associations of America or, "UOAA", is a national network for bowel and urinary diversion support groups in America.

It is a 501 (c) (3) non-profit organization, incorporated in New Jersey, managed by volunteers with the cooperation and utilization of outside professional help when required.

### **What does UOAA hope to accomplish?**

The goal of UOAA is to provide a non-profit association that will serve to unify and strengthen the support groups in America, those former UOA chapters and other hospital based groups, that are organized for the benefit of people who have, or will have intestinal or urinary diversions, and for their care givers.

### **Therefore UOAA's mission is .....**

UOAA is an association of affiliated, non-profit, support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.

It is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large.

It is organized to grow and develop while remaining independent and financially viable.

### **Who can join UOAA?**

Membership in UOAA is open to any former UOA chapter, or support group, such as those that have been formed by a medical professional, hospital or allied agency, that chooses to affiliate with it. Affiliation is also open to the former UOA network groups. Support Groups that affiliate are referred to as "**ASGs**".

### **So then the members of UOAA will be the support groups?**

Yes. You can look at it as an association of associations.

## What about individual memberships in UOAA?

Members of ASGs will be members of UOAA. UOAA will have no national or association members. UOAA will not compete with the ASGs for members!

## With no individual memberships how does UOAA communicate with ASG members and those new ostomy and continent diversion patients looking for information?

- UOAA publishes a quarterly magazine, "**The PHOENIX**", to which ASG members, members of WOCN and any other interested party can subscribe.
- UOAA will display periodic information "**Updates**" on its website, [www.uoaa.org](http://www.uoaa.org).
- UOAA will staff a **Help Line, 800-826-0826**.

## Please explain what you mean in your mission statement when you say "UOAA is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large".

UOAA provides the following:

- **IRS Charity status:** UOAA provides a **501(c)(3) charity status "umbrella"** for its affiliated members. Support groups can take advantage of this coverage (upon indicating they wish to do so) and do not have to apply for their own IRS tax exemption. Under this umbrella, donations made to the ASG may be deducted from the donor's Federal Income Tax.
- **Advocacy:** UOAA continues to serve as an advocate for our community as UOA did in the past. It provides a national forum to unify our voices for the common good of all people with bowel and urinary diversions at local, state and national levels, with emphasis on both private and governmental health care insurance, and on discrimination issues.  
An **Advocacy Hotline** is available via [advocacy@uoaa.org](mailto:advocacy@uoaa.org).  
The "Capwiz" advocacy software is featured on UOAA's website.
- **Information:**
  - UOAA has a comprehensive, interactive website, [www.uoaa.org](http://www.uoaa.org) that includes ostomy information, an advocacy section; and discussion boards for General, Parent, Teen, Young Adult, Continent Diversion, Irrigating Colostomate and International communities. Links have been established to all allied organization websites and to our industry supporters. Bob Baumel serves as UOAA's Webmaster.
  - UOAA has an official quarterly magazine, "**The PHOENIX**", which can be obtained through subscription. The annual cost for a subscription (in the US) is \$ 25.00 payable directly to the publisher. UOAA has contracted with Ian Settlemire, former Editor of UOA's OSTOMY QUARTERLY, to publish

## ***"The PHOENIX".***

- UOAA sends periodic information to ASG contacts, in an electronic newsletter called "UOAA Update". All issues can be viewed at this link: [UOAA Update](#).
- UOAA maintains a library of articles suitable for use in member newsletters, and sends a new selection of articles with each "UOAA Update".
- **Conferences:** UOAA conferences will be held annually, alternating between Regional Conferences one year, and an Annual Conference the next. A very successful inaugural UOAA national conference was held August 2007 at the Lincolnshire Marriott Resort in suburban Chicago. You may [see highlights](#) and some photographs of that event. Regional conferences will be held in 2008 in selected parts of the country (Arizona, New Jersey, Washington state).
- **Referral Service:** UOAA's Help Line is 800-826-0826. People seeking information about rehabilitative support will be directed to their local area's UOAA ASG. UOAA has set up the e-mail address [\*\*ostomyvisitor@uoaa.org\*\*](mailto:ostomyvisitor@uoaa.org). People seeking an ostomy visitor will be directed by UOAA's Office Administrator to an appropriate local ASG or Network.
- **Network Support:** Logistical support is provided as needed and requested to the following virtual Network support groups: the Teen Network; the Young Ostomate and Diversion Alliance of America (YODAA); the 30+ Network; the Continent Diversion Network, and to GLO, the Gay and Lesbian Ostomates. UOAA support the endeavors of the two groups that are separately incorporated and operate as independent entities: the Youth Rally Committee, Inc. [www.rally4youth.org](http://www.rally4youth.org) and Pull-Thru Network <http://www.pullthrunetwork.org/>.
- **Liaisons:** In order to promote better working relationships between the UOAA affiliated support groups and their Allied Agencies, Liaisons are appointed to, and invited from:
  - ACS, ASCRS, CCFA, DDNC, FOW USA, FOW Canada, IOA, National Colorectal Cancer Round Table, The Oley Foundation, The Pull-Thru Network, QLA, The Youth Rally Committee, UOA- Canada, and WOCN.

## **Who manages the business of UOAA?**

UOAA'S Management Board of Directors consists of:

President: Ken Aukett, New Jersey  
President-elect: Kristin Knipp, Ohio  
Vice President: Bob Baker, Connecticut  
Secretary: Mary Jane Wolfe, New Mexico  
Treasurer: Dave Rudzin, Illinois  
Director: LeeAnn Barcus, Missouri  
Director: Charlie Grotevant, Illinois  
Director: Lynne Kramer, Pennsylvania  
Director: Steve Strizic, Washington

Other partners in the operation of UOAA include:

UOAA's Board of Trustees:

Chair: Ron Titlebaum, Massachusetts

Member: George Salamy, New Jersey

Member: Sherry Lessard, Oregon

Office Administrator: Joan McGorry

Advocacy Chair: Linda Aukett

Advocacy Consultant: Colin Cooke

Conference Planning Committee Chair: Kristin Knipp

Phoenix Publisher: Ian Settlemire

Webmaster: Bob Baumel

Each fall, elections will be conducted by mail to fill positions that will be vacant in the coming year. New officers and directors take office on January 1<sup>st</sup> of the following year. To encourage innovative thinking, terms are staggered.

## Who put UOAA together?

UOAA'S Organizing Steering Committee consisted of:

President ... Ken Aukett

Vice President ... Julielyn Gibbons

Treasurer ... Dave Rudzin

Secretary ... Ginnie Kasten

Director ... Charlie Grotevant

Director ... Ron Titlebaum

In addition to the members of the Organizing Steering Committee the following people also helped to organize UOAA: Linda Aukett as Advocacy Chair; Bob Baumel as Webmaster; Ian Settlemire as publisher of "**The PHOENIX** "; Sheldon Sokol as Legal Advisor.

## What is UOAA's Official Address?

UOAA's Contact Office is located in the home of its Office Administrator, Joan McGorry. The official mailing address is **P.O. Box 66, Fairview, TN 37062**. Joan can be reached by telephone at 800-826-0826 or by e-mail at [oa@uoaa.org](mailto:oa@uoaa.org) or [info@uoaa.org](mailto:info@uoaa.org)

## How is UOAA financed?

UOAA receives income from the following:

- UOAA's primary source of operating revenue is the 50% split of **The PHOENIX** subscription fees. The other 50% and the advertising fees go to the publisher who produces the magazine, distributes it, and maintains the subscription list for UOAA.
- The Managing Board of Directors has the right to set an Annual Affiliation Fee, AAF, payable by the ASGs. This fee was waived for 2006. A fee of \$ 2.00 for each member reported to UOAA on the affiliation form was payable on January 1, 2007. The Annual Affiliation Fee for a support group that wishes to join, but chooses not to report any members, is a flat \$ 25.00 per year.

- UOAA solicits advertising for the website.
- UOAA seeks industry sponsorship of key programs.
- UOAA has a Board of Trustees that is responsible for fund raising activities.
- Individual and corporate contributions are also sought. As an example, UOAA is a recipient of funds from the "Get Your Guts in Gear" bike-a-thons that raise funds for charitable entities like UOAA and other IBD related associations, in three bike races. In 2008 GYGIG Rides are will be held in the States of Texas, New York and Washington.

Note: UOAA's operating budget for FY 2007 was approximately \$ 295,000.

### **One question that has not been addressed is that of support group voting rights.**

An ASG will receive one vote for every member that is used in the calculation of its Annual Affiliation Fee. ASGs that do not report any members will be eligible to cast 12 votes. Voting is done by mail to elect members of the Management Board.

### **OK, now that I have read the above information and the UOAA Constitution, how does our group go about affiliating???**

To affiliate with UOAA, complete an Affiliation Form available at the UOAA website (<http://www.uoaa.org/affiliation.shtml>), from the Office Administrator, or from **The Phoenix**. In doing so you are attesting that you have read and understand UOAA's requirements for membership which include:

- Acceptance of UOAA's Constitution and agreement to support UOAA's mission, programs and activities;
- Payment of the Annual Affiliation Fee as determined each year by the UOAA Management Board of Directors;
- Agreement to encourage support group members to subscribe to UOAA's magazine, **The PHOENIX**;
- **Provision of an e-mail address** where communications can be sent; **NOTE: affiliations will not be accepted if an e-mail address is not provided!**
- Agreement that upon dissolution of the group it will give any remaining funds in its treasury to a viable 501(c)(3) charity/s, with strong preference to UOAA, or to other organizations that provide support to ostomates.
- Agreement to have an active patient "Visiting Program"

***"By affiliating with UOAA you will be joining an organization that is dedicated to increasing your viability as a support group, and to improving the quality of life, after surgery, of your group's members and the ostomy/continent diversion community it serves."***