



United  
Ostomy  
Association, Inc.

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# Annual Report 2003

Mission: The UOA is a volunteer based health organization dedicated to providing education, information, support, and advocacy for people who have or will have intestinal or urinary diversions.

## President's Message



Ron Titlebaum  
UOA President  
2002-2004

Despite dramatic developments in surgical alternatives and disease prevention programs, many individuals with colorectal or bladder cancer, birth defects or inflammatory bowel disease will need an ostomy or a continent diversion procedure. With 75,000 ostomy-related surgeries every year, the need for UOA and its services continues. For 41 years, people faced with the frightening realization of a bowel or urinary diversion have turned to the United Ostomy Association. Building on its tradition of service, UOA continues to provide people with information, education, advocacy and support.

UOA's Strategic Plan focuses on four pillars: service to Youth; Advocacy for all individuals with an ostomy or related procedure; Leadership and organizational development including expanded fund raising; and the Education of our constituents and their caregivers. We made major progress in each one of these areas in 2003.

To facilitate youth services, **UOA expanded its existing but parallel concept of national networks to complement over 400 local chapters**, reaching new individuals in differing demographic groups, but still connected by their surgery and its issues. Networks are "virtual chapters" that serve national rather than local constituencies. Scattered around the country, they communicate by e-mail and the Internet, as well as via more traditional methods.

In July 2003, immediately following our very successful 25th Annual Youth Rally in St. Paul, MN, UOA held its first-ever Young Adult Conference. With nearly 100 attendees aged 18–25, the UOA Young Adult Network was overwhelmingly enthusiastic and will repeat the conference by integrating it with the 2004 UOA national Conference in Louisville. At the UOA National Conference, our four youth networks and our Continent Diversion Network programmed their own "track" or conference-within-a-conference. Our Parents Network track alone had a record 82 attendees. Last year, we also launched the UOA Teen Network aimed at individuals between 11–18. The Teen Network developed their own message board and a teen section of the Ostomy Quarterly.

UOA recognized long ago that the Internet was evolving not just as an education and communications tool, but also as a connecting element for people with common interests. Our Web page, [www.uoa.org](http://www.uoa.org), was redesigned in late 2002 and is now the premier source for ostomy information and advocates of ostomy services and support. **Last year, over 33,000 people visited our site on a monthly basis**, and our four discussion boards enjoy heavy traffic.

We are now processing memberships and accepting donations online. In 2003 we introduced an online archiving service allowing UOA chapter leaders to download the latest articles on ostomy care for inclusion in their local newsletters. In December, our Web site

UOA's advocates sent a total of 1,524 messages to Congress and others last year. Most of these were sent by e-mail but many also used our online service, Capwiz, at [advocacy@uoa.org](mailto:advocacy@uoa.org) to print out and mail their letters. **Of special note, in 2003 UOA was instrumental in forming a new ostomy advocacy coalition** joining manufacturers, distributors, UOA members and other parties together to support our mission. UOA was also very active in the area of disease prevention by meeting with related organizations fighting cancer, IBD and other digestive diseases.

Communication with UOA chapters and leaders was expanded via The Insider and Behind the Scenes newsletters, and we introduced Web Site News to over 6,000 voluntary subscribers. Nancy Italia, executive director and I met in the field with over 30 chapters in six metro areas to exchange ideas. To further relations, our national leaders also visited with the leading manufacturers and distributors of ostomy supplies as well as with our medical partners, most notably the Wound, Ostomy, and Continence Nurses Society, the Crohn's and Colitis Foundation of America and the American Cancer Society.

Despite the difficult economy, **UOA had its best fund-raising year in over a decade**, receiving more than \$500,000 through various donor programs. Of special note, we received two grants from the Bristol-Myers Squibb Foundation totaling \$70,000. One of these will sponsor a feasibility study to review and further improve our income development programs. It is significant that UOA received dedicated funds to translate and publish our seven comprehensive patient care guides into Spanish in 2004.

UOA is deeply grateful to its corps of national and local volunteers and to its central office team for accomplishing so much and for committing to do so much more. Each time we meet a new ostomate, whether online or in person through our chapter meetings or visitors program, we reinforce the need for UOA and its mission. We are making a difference in the lives of so many people as we help them understand that an ostomy or related diversion is merely a side step from disease to a satisfactory and productive life.

UOA expanded service to age-based networks, including parents, children, young adults and the thirty-plus age group

## Youth

The strategic plan of the United Ostomy Association directs activities that expand and improve UOA educational and support services to all members and networks; intensify marketing and increase membership; strengthen the national organization, its chapters, networks and the central office and improve advocacy services and prevention activities. As such, this report focuses on our four areas of service and programs designed for youth, advocacy, leadership and education.

- Twenty-seven families attended the UOA National Conference in Las Vegas, including eight who were sponsored by the new \$10,000 Parents Scholarship Program that assisted with travel and registration expenses.
  - The first-ever **Young Adult Conference** attracted over 100 participants and exhibitors in St. Paul, MN, July 17–19. The success of this program guaranteed annual continuation.
  - The **Thirty-Plus Network** pioneered its **Ambassador** program at the national conference in Las Vegas, wearing flashing-light necklaces and offering advice and friendship to conference attendees.
  - The **Teen Network Discussion Board** was launched in September and has become a popular electronic meeting place for 11–17 year-old youth to discuss common challenges and successes. Teen Network committee members added new resources to their Web page and the Ostomy Quarterly. A Teen Mentoring program was initiated in July.
- "I always felt so alone, now I feel like a part of a big family."*  
-Young Adult Conference Participant from New York



2003 UOA Youth Rally Group

# Advocacy

UOA is dedicated to improving advocacy services and prevention activities

- The latest **Medicare codes and fees** for ostomy products were updated on our Web site, reflecting the positive influence of the Government Affairs Committee (GAC). The GAC also orchestrated a campaign to advise Congress of the burden of **competitive bidding**, resulting in a delayed timeframe for implementing the bidding system.
- Through UOA's Web site service **Capwiz**, provided by Capitol Advantage, members sent 1,524 messages to Congress on topics of interest to UOA and its members.



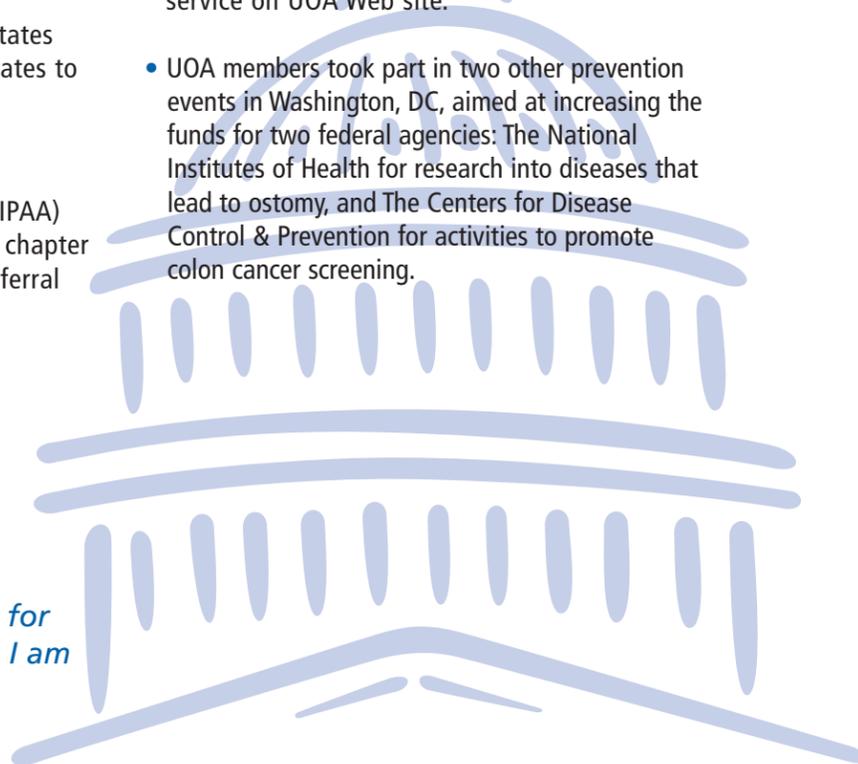
- UOA purchased **LegAlert**, a service that **scans state and federal legislative activity** using selected key words. This service alerted the GAC of previously unknown

insurance-coverage related bills in three states and will help identify members in these states to involve in advocacy efforts.

- Information on the **Health Insurance Portability and Accountability Act (HIPAA)** was posted on our Web site and sent to chapter presidents, along with a UOA Patient Referral Form for chapter visiting programs.

*"Thank you for all you are doing for ostomates, both young and old. I am 91 years old. I salute you."  
- A California member*

- UOA joined with the American Association for Homecare, Byram Healthcare, Choice Medical, ConvaTec and Hollister, Inc. to create a **coalition to improve Medicare reimbursement schedules**.
- An 800 telephone number service offering **mental health and social work consultation** to those in need of professional psycho-social assistance was introduced in May.
- UOA continued its commitment to **Prevention Activities through collaboration** with the American Cancer Society, participation in the National Colorectal Cancer Roundtable and the Colon Cancer Alliance Conference and promotion of the Colossal Colon Tour. We supported cancer research legislation through One Voice Against Cancer and the Capwiz service on UOA Web site.
- UOA members took part in two other prevention events in Washington, DC, aimed at increasing the funds for two federal agencies: The National Institutes of Health for research into diseases that lead to ostomy, and The Centers for Disease Control & Prevention for activities to promote colon cancer screening.



# Leadership



*Ann Favreau (second from left) received the Sam Dubin Award, UOA's highest honor. She is joined by previous winners (left to right) Gail Smuda, Bobbie Brewer and Marilyn Mau.*

UOA strengthened the national organization, its chapters, networks, and central office.

- The **Sam Dubin Award** was presented to a very worthy **Ann Favreau**, past president, for her volunteer work at the national level, and the **President's Award** was given to Government Affairs Chair and tireless advocate **Linda Aukett**. **Liz Lemiska**, Middletown, CT, received the **UOA 2003 WOC(ET) Nurse of the Year Award**, and the **Archie Vinitsky ET Scholarship** was given to **Mary Sweeney**, Dubuque, IA.
- A **newsletter article service to chapter newsletter editors** was initiated in September. More than 200 **short articles** organized in 30 main subjects were posted on the UOA Web site. This members-only collection is expanded regularly.
- **UOA chapters were surveyed** to profile their characteristics, including chapter members, meetings, newsletters, Web sites, visiting programs, etc. Results were presented in the *Ostomy Quarterly*.
- A special **Leadership Track** for chapter leaders was part of the national conference in August. Sessions included Revitalizing Chapter Meetings, Promotion Strategies for Chapters and Utilizing Internet Resources.
- UOA leaders embarked on a **"Meet the Chapters"** program to visit chapters in Wisconsin, Northern California, Pennsylvania, New Jersey, Delaware, New York and Connecticut. Good fellowship, information and success stories were shared.
- **Chapters** in a tri-state area from greater Philadelphia; Lower Bucks County, PA; Southern New Jersey and Delaware collaborated to develop **shared regional resources** such as a toll-free telephone hotline, visiting program, linked Web sites and plans for a regional conference. This model can serve other urban areas where there are several chapters in close proximity to each other.

- In a very difficult fundraising environment, UOA's **Income Development activities** resulted in the most successful year ever. More than **\$500,000** was raised through direct mail campaigns, planned giving, the Call Team program, memorials and tributes, grants, the Chapter Participation program, endowment fund, e-commerce and vehicle donations. Grants were received to support the Youth Rally, translation and distribution of patient care guides into Spanish, office technology and a fundraising feasibility study. New ventures were made in e-commerce through an online shopping program with Amazon.com and Barnes & Noble Booksellers, and twice-monthly auctions were held on e-Bay to sell Thomas Mangelsen wildlife photographs.

*"I feel we have FINALLY found a place where we can share our story. After five long, heart breaking, devastating years, I have my hopes up."  
- A Texas ostomate who has connected to a UOA chapter*

- UOA's financial audit confirmed that \$.78 of every dollar was spent on programs. This admirable percentage illustrates a well-managed commitment to serving our mission and allows UOA to qualify for grants and government programs
- **Get Your Guts in Gear**, a 210-mile, three-day bicycle ride in New York State, will raise funds and awareness for research, education and advocacy to assist IBD patients was announced. Proceeds will be shared by UOA, Crohn's & Colitis Foundation of America and the IBD Quilt Project. UOA's Director of Communications Ian Settlemire will be the official UOA rider.



# Education

*"Thanks for the Web Site News! It is informative and upbeat!"*  
- A Wisconsin member



UOA and Friends of Ostomates Worldwide volunteers recognized at national conference.

- **Orthotopic Neobladder—A Surgical Option for Bladder Diversion**, a new brochure, describes the new procedure to create a bladder when the original bladder is removed.
- **The Spouse and Family Support for Ostomates** brochure was published to explain the important role of a spouse or family member in the rehabilitation process of an ostomate.
- **Cymed Ostomy Co., Nu-Hope Laboratories, Hollister, Inc., and Marlin Medical Group, LP** generously provided funding to translate UOA's **seven patient care guides into Spanish**. A subsequent grant provided funds to print and distribute the guides in Southern California. In addition, **six of UOA's free educational brochures are now available in Spanish** on the UOA Web site.
- The **Ostomy Quarterly** magazine published its second special feature issue in the summer on advocacy. In addition, each issue included personal stories, reports by UOA's six networks, examples of chapter success stories, medical information and advice, income development campaigns and product and supply advertisements.
- UOA president's **Behind the Scenes national** news and the central office monthly newsletter, **The Insider** were issued electronically, on Web site and via chapter mailings.

- Over 700 members and exhibitors enjoyed **UOA's National Conference in Las Vegas** August 10–13. The flavor of the conference was greatly enriched by the many small children and their parents, teens, young adults and "J-pouchers" attending special sessions targeted to their needs. Members from all over the U.S. attended programs ranging from stress management to understanding lab reports to estate planning and chapter management.
- UOA presented the fourth in a series of **Ostomy Education Seminars** in May in Philadelphia, with the support of ConvaTec. The purpose is to educate members of the medical healthcare community who are caring for ostomy patients.



UOA brochure in Spanish.

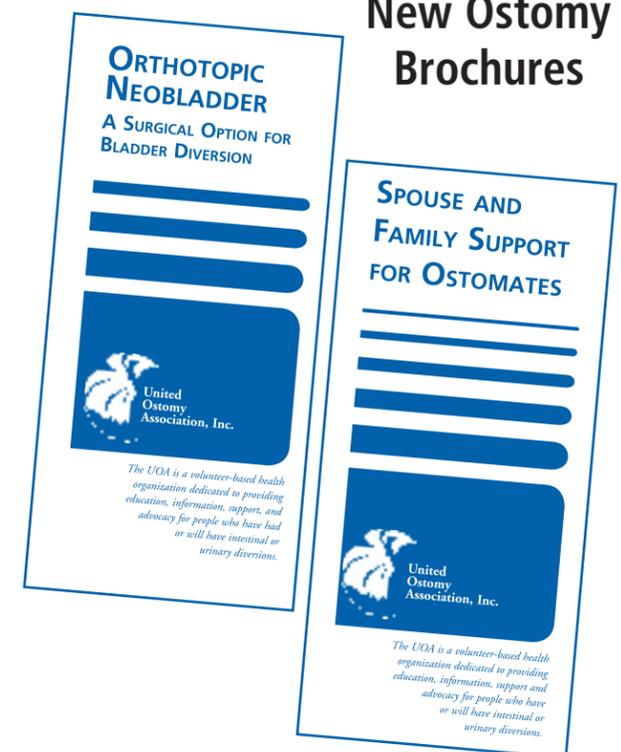
UOA Provided Information and Education to Its Members and Prospective Members



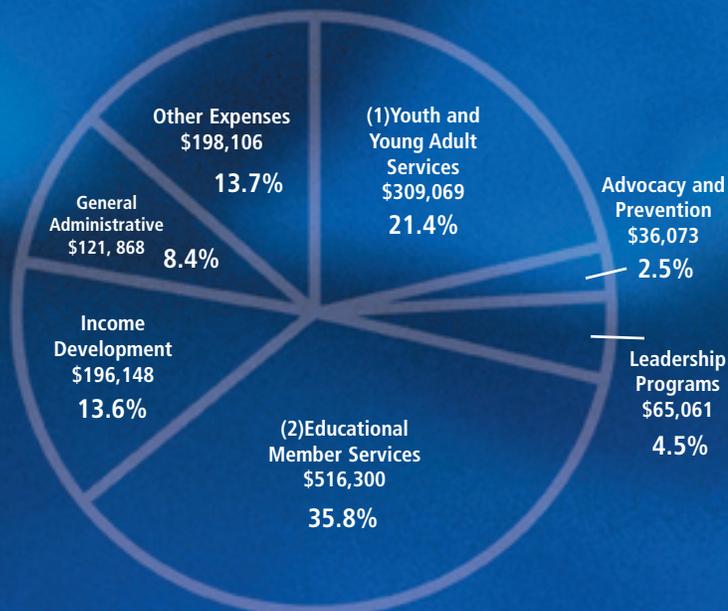
*"You are helping so many people with this Web site. I cannot thank you enough... I rely more on this site than the so-called professionals to whom I pay a lot of money."*  
-Discussion Board user.

- UOA's Chattanooga chapter hosted a **Southeast Regional Meeting** in October where over 65 people attended.
- A monthly electronic communication, **Web Site News**, describing UOA products and services and new content on the Web site, was initiated in January and is currently sent to over 6,000 people.
- The UOA Web Site won a prestigious **2003 Aesculapius Award of Excellence** from the Health Improvement Institute for excellence in informing consumer lifestyle choices and health care decisions. The site is receiving over 1.5 million "hits" per month, reflecting over 400,000 pages viewed by 33,000 visitors.

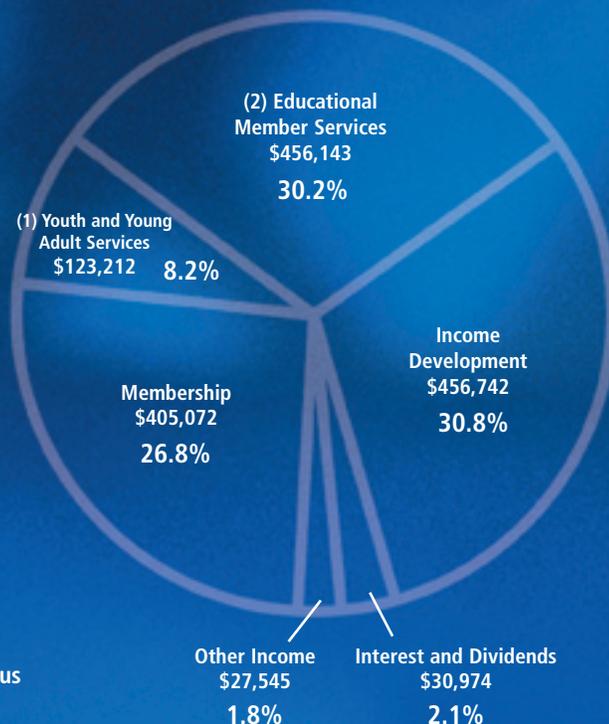
## New Ostomy Brochures



## EXPENSE SUMMARY \$1,442,615



## REVENUE SUMMARY \$1,510,432



<sup>1</sup> Includes Youth Rally, Young Adult Conference, Parents, Teens, Young Adults, Thirty-Plus

<sup>2</sup> Includes OQ, National Conference, Publications, Internet, Donated Services

## UOA FUNDING OVERVIEW

### Four Designated Funds

For UOA to thrive and grow, the following funds must also grow:

**Youth/Young Adult Fund** - Parents Network, Youth Rally, Teen Network, Young Adult Network, Thirty-Plus Network.

**Advocacy and Prevention Fund** - Advocating for individuals at the national and local level, disease prevention.

**Leadership Fund** - National and chapter leader development, and training for board members, network leaders, and field service personnel, central office support.

**Education Fund** - Education for members, caregivers, chapters, networks, the ostomy community at large, and the general public.

## 2002-03 UOA Board of Directors

**President:** Ron Titlebaum, Danvers, MA

**Vice President:** Dean Arnold, Winnebago, IL

**Treasurer:** Brian Bowden, Vista, CA

**Secretary:** Ginnie Kasten, Glen Ellyn, IL

**Immediate Past President:** Ann Favreau, Venice, FL

### Board Members:

Michael Carlson, Bloomington, MN

LeAnna Guerin, Carthage, MO

Beth MacKenzie, Boston, MA

Bonnie McElroy, Hoover AL

LaVerna Reid, Edmond, OK

David Rudzin, Buffalo Grove, IL

Barbara Schmidgall, Mason, MI

## UOA Staff

**Executive Director:** Nancy Italia

**Director of Communication Services:** Ian Settlemire

**Director of Development:** Roger Rustad

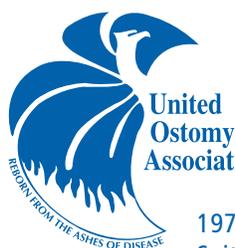
**Director of Finance:** Coriene Banner

**Director of Program Services:** Jean Smith

**Membership Coordinator:** Shelai Siets

**Administrative Assistant, Fund Raising and Publications:** Barrett Rustad

**Receptionist:** Sandra Stephens



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