



A Look At Ostomy Patient Peer Group Support * 72 Years of Progress and Still Going Strong *

By Ken Aukett and Rev. Anthony Giordano with Input from George Salamy

A “stoma” has once been described as a new beginning with the end in view. In this history we will look at three new beginnings of ostomy patients helping each other to find a positive post-op quality of life; 1) We follow the growth of this form of peer group therapy from its beginning in a conference room with four chairs around a table; 2) Through expansion to an ostomy patient, volunteer governed, incorporated, non-profit, national association, with local affiliated chapters; and, 3) To, upon dissolution of the first national organization, the beginning of a new association, organized to further serve the present and future psychological, rehabilitation and stoma management needs, both pre-op and post-op, of colostomy, ileostomy, urostomy and continent diversion patients and their caregivers.

Back in the 1940s, due to problems with ostomy surgery techniques, hospital stays of two months or longer were the norm. As a result, ostomy surgery was being done in only a few medical centers in the US and Canada. Ostomy equipment was unsophisticated and extremely limited. Bulky, leaky and odorous, stoma management products were a great deterrent to patient acceptance of their ostomy surgery and to their rehabilitation process. When available, rubber, reusable drainable pouches were cemented onto the patient's skin over a piece of intestine that penetrated through the patient's abdomen (a stoma) to collect their bodily waste.

In 1949, four World War II veterans, who were ostomy patients, met in the Veterans Hospital in Valley Forge, Pennsylvania, to exchange information about stoma management based on their life experiences. Meeting to provide psychological support to each other, these four men discussed how to live a productive life with an ostomy. In talking to one of these pioneers who had had ileostomy surgery, he described how he would wrap a bath towel around his waist, button up his shirt, and then sit in the back row of his class at the University of Pennsylvania.

These meetings of veterans were the first known attempt at mutual aid. From this start, other ostomy patient support groups throughout the United States and Canada were formed by patients, progressive doctors and nurses. Early groups met in New York, Philadelphia, Boston, Metro Maryland, Chicago, St. Paul, Toronto, and Los Angeles. These volunteer-staffed groups, managed largely by ostomy patients with the support of medical staff, began to advocate on behalf of all

ostomates. They put the medical community's spotlight on the quality of life attainable by a person with a fecal or urinary stoma. One such group met in Mt. Sinai Hospital in New York City with male and female ostomy patients from the hospital's wards "Q" and "T" as meeting attendees. Since talking about fecal or urinary medical procedures was not then, and even now, a socially accepted practice, the group used the name "QT". Thereafter, many of the other early groups that formed adopted the "QT" moniker.

In 1962, delegates from 24 of these peer-led ostomy patient support groups from the United States and Canada met for an ostomy conference in Cleveland. At that convention, they approved a motion to establish the United Ostomy Association (UOA), an organization they formed to serve as a multi-national network for bowel and urinary diversion support groups.

For the next 43 years UOA's Regional Program volunteers, under the direction of its National Leaders, assisted in the formation and subsequent affiliation of over 500 local support groups in the United States, Canada, Puerto Rico and Bermuda. UOA's membership consisted of individuals. In 1986 UOA reached its highest membership with approximately 50,000 dues-paying members. This membership consisted of people who had undergone ostomy surgery (ostomates), their caregivers, family and friends, members of the medical community, ostomy product manufacturers and distributors.

During the '60s, '70s and '80s, advancements were made in the development of stoma management products. They were more "skin-friendly", odor resistant and disposable. A major step also took place in the medical community with the training of specialized ostomy/stoma nurses, professionally known as Enterostomal Therapists or ETs. These nurses organized the International Association of Enterostomal Therapists or IAET. Later, with the advent of additional professional education, technological advances in medical procedures and new standards of patient care, the IAET re-organized and became the Wound, Ostomy, and Continence Nurses Society, or WOCN Society.

The 1990s and the early years of the 21st Century saw advances in early colon cancer detection, new surgical procedures, improved drug therapies, and the promotion of product and care information by ostomy product manufacturers. These factors coupled with the formation in 1997 of a national ostomy association in Canada, n.k.a. the Ostomy Canada Society, and the advent of social media, resulted in a significant drop in the number of dues-paying members enrolled in UOA.

The most pressing issue facing the Board of Directors was the funding of the UOA's operations each year. This problem was compounded by its fiscal policy that required the UOA to spend the funds it raised in the fiscal year in which they were raised ... i.e., no carry over! Strategic projections were made about future income, and operating expenses. While membership dues were declining, donations tailing off, corporate support diminishing; UOA's operating expenses were steadily increasing. In 2004 and 2005, it became apparent that the organization would have to make a heartbreaking, drastic decision.

In May 2005, Ken and Linda Aukett, both of whom had served as UOA Presidents, received word that to avoid bankruptcy the Board had voted to close its doors for good on September 30th, 2005.

This decision made economic sense but created a void impacting the existing and future ostomy communities. Without a national presence, the advocacy work undertaken by UOA would cease to exist. Who would represent and advocate for the common ostomate in State, Federal, Insurance and Corporate worlds? The ostomate's voice would be silenced. Without a national organization, there would be no 800 helpline or internet website for people to turn to for information about support groups or a forum to discuss living with an ostomy. Who would publish a magazine to replace the *Ostomy Quarterly*? Who would convene ostomy conferences that were structured for the lay attendee, or provide the ostomy patient groups with an umbrella of support including IRS non-profit tax-exempt charity status and above all, a sense of solidarity?

Linda had established herself as a well-respected advocate for the ostomy community. Ken had served as President of the International Ostomy Association (IOA), which consisted of national ostomy associations in 74 countries. They knew that a volunteer-managed association of associations could work on limited start-up finances. They would use IOA as a model for a new organization's structure and constitution.

A Steering Committee was quickly formed with the goal of filling the organizational void that would be left by the upcoming dissolution of UOA. Utilizing the 43 years of good-will and name recognition achieved by UOA, "**United Ostomy Associations of America**" (UOAA) was selected as the organization's name. The membership of UOAA would consist of its affiliated support groups (ASGs) with members of the ASGs looked upon as members of UOAA. UOAA therefore, is an Association of Associations, ergo its name. On October 1st, 2005, UOAA opened its doors ... "A New Beginning".

Ken and Linda Aukett have been formally recognized by UOAA's Board of Directors, as its Co-Founders.

The Steering Committee also approved the continued use of the Phoenix as the organization's symbol, a symbol that embodies the act of "*rising from the ashes of disease*".

The constitution for the new organization was written and incorporated in the State of New Jersey, organized exclusively for charitable, educational and scientific purposes. Under Section 501(c)(3) of the IRS code, "charity status" was obtained. In a later submission to the IRS, the affiliates of UOAA, its ASGs, can, upon request, be granted 501(c)(3) charity status under UOAA's umbrella. UOAA is a non-political, religiously neutral organization, concerned only with the health and welfare of ostomy and continent diversion patients and their caregivers regardless of their gender, race, creed or sexual preference.

UOAA's vision is to have a society where people with ostomies and intestinal or urinary diversions (colostomies, ileostomies, urostomies and continent diversions) are universally accepted and supported socially, economically, medically and psychologically.

UOAA is organized to carry forth and expand the previously established advocacy initiatives and to unify and strengthen its ostomy patient support groups (ASGs) by providing them with services they could not attain themselves. UOAA promotes the formation and affiliation of new ostomy patient support groups and provides programs to ensure that they remain viable and capable of carrying out UOAA's mission *"To promote the quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration."*

Policy determinations and the governance of UOAA are the responsibility of its Board of Directors. This Board consists of: President, President-Elect, Treasurer/Legal Secretary, Director of Affiliated Support Group Affairs, Director of Young Ostomate Outreach and Directors at Large. Advice and Counsel is provided to the President by the Immediate Past President.

The day-to-day organizational activities of UOAA are undertaken by a professional, paid staff. UOAA's Office is presently situated in Kennebunk, Maine. In addition to an Executive Director, UOAA's Staff consists of an Advocacy Manager, an ASG and Program Coordinator, a Communications and Outreach Manager, a Webmaster, an Office Coordinator and an Office Assistant. Contractors are utilized on an as-needed basis.

Volunteer-staffed committees are formed to carry out specific activities to enable UOAA to better serve the ostomy community at large. They include the Advocacy Committee, the Finance Committee, the Education Committee, the Conference Planning Committee, the Nominations and Elections Committee and the Medical Advisory Board. From time to time ad-hoc committees are appointed.

UOAA has a contract with an independent contractor, to publish its quarterly issued magazine, ***The Phoenix*** and its ***New Ostomy Patient Guide***, a magazine that is provided to the medical community free of charge for distribution to their ostomy patients.

UOAA has the internet's most comprehensive ostomy-related website, www.ostomy.org, designed for those seeking educational and motivational information about all things "ostomy" and UOAA services. UOAA's telephone number, **800-826-0826**, secured from UOA, has been in existence since 1992 and is widely recognized and utilized by the nation's ostomy and medical communities.

UOAA convenes national conferences usually every two years and encourages its Affiliated Support Groups to host regional conferences in years when there is no national conference. It actively supports activities of the Youth Rally Committee, Inc. (YRC) and their efforts to identify "camp" attendees. Each year the YRC hosts kids and teens living with conditions of the bowel and bladder. This one-of-a-kind camp experience promotes independence, self-esteem, learning, friendship and FUN! UOAA also promotes the sharing of donated ostomy supplies to 3rd World countries by the Friends of Ostomates Worldwide-USA (FOW-USA), and to other groups that makes available ostomy supplies to those ostomates who have fallen on hard times.

UOAA is an active member of the International Ostomy Association (IOA) and its Regions, including the Ostomy Association of the Americas (OAA), and its sub-region, the North and Central America and Caribbean Ostomy Association (NCACOA). Working relationships have been formed

with kindred organizations such as the Wound Ostomy Continence Nurses (WOC Nurses) Society, the American Society of Colorectal Surgeons (ASCRS), the Crohn's and Colitis Foundation (CCF), the American Cancer Society (ACS), the American College of Surgeons (ACS), the Digestive Disease National Coalition (DDNC), the Youth Rally Committee and the Wound Care Education Institute (WCEI).

UOAA acknowledges the support and mutually beneficial working relationships developed with the manufacturers and distributors of ostomy management products.

Through the provision of service to a community of 725,000 to 1,000,000 people living in the United States who have undergone ostomy surgery and the 100,000+ new ostomy surgeries each year, United Ostomy Associations of America has been acknowledged as a humanitarian organization that touches the lives of countless individuals, giving them hope and the knowledge that the quality of life they experience after ostomy surgery can be all they want it to be.

Authored by:

Kenneth (Ken) Aukett

- Organizer and Past President, Ostomy Association of Southern New Jersey
- Past President, United Ostomy Association (UOA)
- Organizer and Past President, North and Central America and Caribbean Ostomy Association
- Past President, International Ostomy Association (IOA)
- Co-Founder, Past President, United Ostomy Associations of America
- Founder, Past President and current Treasurer, Ostomy Association of the Americas (a Region of IOA)
- Past Chair, Coordination Committee, International Ostomy Association

Reverend Anthony Giordano, UOAA Director at Large

With historical input contributed by George Salamy

- Past President Ostomy Association of NY
- Past President of Morris County NJ Ostomy Association
- Past Vice President and Treasurer of United Ostomy Association (UOA)
- Past Treasurer of United Ostomy Associations of America (UOAA)
- Past President of North and Central America and Caribbean Ostomy Association of the Americas (a region of IOA)
- Treasurer of North and Central and Caribbean Ostomy Association

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