

North & Central American and Caribbean Ostomy Association

VOLUME 8, ISSUE 1

SUMMER, 2006

From the President of the NCACOA, 8 August 2006

Dear Friends,

As persons who have undergone surgery to create an ostomy or other diversion, we find comfort in meeting others who have gone through that process. Ultimately we gain strength from those relationships, which helps us move forward to normal life. We can then turn to help the next person who sets foot on this unique journey.

Similarly, the groups that thus form gain benefit and strength from joining together – from ‘associating’ with like groups. It is this banding together that has led to the development of national associations around the world. Within those associations, member groups learn from each other and work together to found other member groups, so that their assistance can reach other countrymen.

The NCACOA represents the next step. Within this regional association, it is hoped that our 10 member associations will combine their resources and energy to help each other, and to help other countries establish ostomy rehabilitation services for their own people. There is certainly still work to be done in Central America and the Caribbean countries.

In the past year, our region faced a unique challenge – finding a way to help one of our members reshape its national presence so that ostomy services, support and advocacy would again be assured to all its residents. Since this was happening within my own nation (the US) and indeed within my own household (my husband was the one who led the reorganization of a US association), my time and attention was largely devoted to that endeavor.

Further, it became a personal mission to help the former UOA program for teens, the Youth Rally, to survive and continue its important aid to youth living with a bowel or bladder diversion. I must apologize that I allowed communication with the existing NCACOA member organizations to suffer in favor of these two groups that, I felt, needed my attention more.

Communication is a 2-way street, though. Presented here the results of a June communication to **ALL 10** member organizations of NCACOA. It is regrettable that only 4 have provided reports to share with their fellow-associations. Thankfully we had some slightly earlier tidbits of news from 2 others. We have faith that the other NCACOA members are actively pursuing their objectives to improve the lives of ostomates in their countries – but it would be good to have news of their activities and advances to share with all.



Best regards to you all, until we meet in Puerto Rico in August, 2007!
Linda

INSIDE:

- ◆ **REPORTS FROM**
 - CANADA
 - PUERTO RICO
 - TRINIDAD & TOBAGO
 - UNITED STATES
- ◆ **REGIONAL FINANCIAL STATUS**
- ◆ **WORLD OSTOMY DAY - 7 OCT**

NCACOA OFFICERS:

Linda Aukett, President (USA)
P.O. Box 318, Collingswood NJ 08108 U.S.A.
Tel : +856-854-3737
E-mail : buffaway@snip.net

Doug Graham, Vice President (Canada)

Fernando Ferrar, Executive Council Member (Panamá)

Martha Velez de Nieves, Immediate Past President (Puerto Rico)





UNITED OSTOMY ASSOCIATION OF CANADA

Some of the big challenges that UOAC has faced this past year are expansion and retention of membership, public awareness, fund-raising, and working together with industry.

New corporate identity project:

To aid in these endeavours, in March 2006, UOAC successfully launched our corporate identity project. We worked together with the University of Saskatoon in Saskatchewan to produce a video about living with an ostomy. This video will help brand and market UOAC to a whole new group of people and help us to raise funds.

Approximately 30 people participated at the first showing of the video in Saskatoon Saskatchewan. A brief overview of UOAC and what we do, was presented to those in attendance. We also shared the future plans for the second phase of the project. ConvaTec, a platinum sponsor of the video, also provided some insight on their partnership with UOAC. A second launch for the membership will be held at our annual conference in Moncton, New Brunswick in August.

New group for parents:

We intend to initiate a new group for parents of children with ostomies and special related needs in the next few months. Parents of children with special needs require support as well as ostomates and we hope to develop a program to meet their specific needs.

Ongoing activities:

Our Publications committee has been working on reviewing UOAC publications and investigating new ones. Maintaining a good choice of publications is a great way to promote public awareness and add a valued service to our members who in turn can help ostomates in their own communities.

Our SASO Committee (Spouses and Significant Others) have increased their contacts within chapters across Canada and are planning sessions at our national conference in August. Many chapters are training SASO members at visitor training sessions along with ostomates so that they may offer the same support to spouses and significant others of patients.

UOAC recently provided IOA with a copy of our Visitor Training Program to aid in the development of a similar program for IOA.

The Strategic Planning and Executive meetings were held in Toronto in April. We accomplished a great deal during those meetings, including a working, balanced budget, improvements to the District Support Services committee, fund raising and more.

In May, Vice-President, Doug Graham represented UOAC at the annual conference of the Canadian Association for Enterostomal Therapy. This provided an opportunity to display our available publications, answer questions about our association and meet with manufacturers and ET nurses from across Canada.

Youth Camp:

July brings our Youth Camp. This event is the highlight of the year for many young people across Canada. In January, I started receiving requests from children wanting to return to the camp again this year. We hope to have 34 children, from across the country, attend this year's camp.

We also have a home and automobile insurance initiative in the works where members who sign with a partner insurance company, UOAC will receive a percentage of the premiums.

Conference:

Our Annual Conference will be held in Moncton, New Brunswick August 17 – 19, 2006. The planning committee have worked hard to bring us a great conference with interesting and diverse speakers, entertaining sessions and some fun thrown in. Everyone looks forward to the exhibit hall where we all have the opportunity to view and request samples of new products that the manufacturers and other vendors of ostomy related products have on display.

World Ostomy Day:

The fall will bring World Ostomy Day. Canada has three major events that will be celebrated nationally. First is our Annual Golf Tournament. This year it was decided to hold this event in conjunction with World Ostomy Day. The venue was also changed to a high profile golf course, Glenn Abbey, in the hopes of raising more money, giving potential golfers a chance to play on Canada's most prestigious course and to raise ostomy awareness at the same time.

October 7, UOAC will host a celebration at Toronto City Hall. This celebration will include speakers, the manufacturers and other dignitaries coming together to promote ostomy awareness.

The third event will be a national bowl-a-thon. For those who aren't familiar with a bowl-a-thon, this is an event where people get together to bowl for charity. The event will be fun, raise funds for the local chapters who participate and promote public awareness of the ostomy experience. The chapters who choose not to hold a bowl-a-thon can hold an event that will best suite their volunteers in order to promote World Ostomy Day. All in all a very eventful few days.

UOAC wishes everyone in the different IOA Regions, success with their own World Ostomy Day celebrations.

We look forward to a very busy summer and fall full of good health and prosperity and we wish the same for all of you.

Pat Cimmeck, President

ASOCIACIÓN de OSTOMIZADOS de PUERTO RICO



Our association has been very busy after returning from the World Congress in Porto which was held on August 2004. We are proud to be the host of the next 12th World Congress. On February of this year we received the visit of our President Di Bracken and IPP Heinz Wolff in order to select a new venue for the World Congress. We selected the Fajardo Inn and the World Congress will be held from August 7th – 12th, 2007.

We invite all member of our region to come to this congress as it will be a different atmosphere and full of interesting workshops. I'm sure you will enjoy your stay and will be able to meet ostomates from around the world, so mark your calendar and don't miss this opportunity. I would like to inform those of you who are not US Citizens that you will need to request a Visa to enter Puerto Rico. If this is your case please let me know, as I will send you an invitation letter for this purpose.

I want to take this opportunity to congratulate Linda Aukett for being elected as our Regional President. Linda has worked for many years advocating for ostomates. I also congratulate Doug Graham and Fernando Ferrer for being elected to be part of the EC of NCACOA Region, and last but not least, I want to thank Marilyn Mau for the wonderful work she performed as Immediate Past President and for her support when I needed to know about history and procedures in NCACOA. I'm sure that with the expertise of this new group we will be able to achieve many things in our region.

Our local group has been very active participating in different activities related to colorectal cancer awareness. We are working together with the Comprehensive Cancer Control. They have formed a partnership with different organizations to develop the Puerto Rico Cancer Plan for Year 2007. This plan will be the official guideline for all people working with cancer patients.

The Puerto Rico Colorectal Cancer Coalition is working with the National Cancer Institute's Cancer Information Center, and as part of the Colorectal Cancer National Awareness month, CIS partnered with the American Cancer Society, Puerto Rican Gastroenterology Association, the Oncology Nurses Society, The Puerto Rico Ostomy Association, the Puerto Rico Cancer Center, and Sanofi-Aventis to establish this coalition and develop colorectal cancer projects promoting colorectal cancer and early detection and prevention.

The first initiative was "Save our Parents". This educational program targeted 176 high school students, who learned about colorectal cancer prevention using an interactive hand on model of how to perform a colonoscopy. The students then entered into a contract agreement with their parents asking them to undergo colorectal cancer screening. The program was the initial phase of a pilot project for a wider educational initiative in Puerto Rican High Schools. It is expected that 400 high schools students throughout the island will be participating in this initiative. The outcomes of the program will be measured by a combination of pre- and post-tests, completion of the

contracts and participation in this program. Information gathered from this initiative will be analyzed and will be the basis for inclusion of colorectal cancer prevention education in the PR High School Health Curriculum.

Another colorectal cancer awareness is being planned for the month of November, this time we will target the family members of those who have been diagnosed with colorectal cancer. This will be held at the facilities of a University.

AOPR also participated in Relay for Life a national event of the American Cancer Society. We walked twelve consecutive hours at Central Park of San Juan. Our ostomates participated and were very proud of this fundraising event. This was the 10th edition and we have been participating in all ten events.

A group of ostomates volunteer at the cancer center of Auxilio Mutuo Hospital. They visit people who are receiving chemotherapy and also our visiting program is running at this hospital. This group also visits different hospitals in the metropolitan area.

Our volunteers continue supporting the American Cancer Society with their weekly Ostomates Rehabilitation Clinics in San Juan, and once a month in Mayaguez and Arecibo. They plan to expand this service to another two cities, and we will also be able to support them with our volunteers.

I have been selected as Ambassador for Celebration on the Hill a national event of advocacy for cancer patients. We will bring to Washington a delegation of approximately 30 people and will have the opportunity to speak to our Resident Commissioner Luis G. Fortuño about the work we do in Puerto Rico and the needs of cancer patients.

On October we will be celebrating World Ostomy Day. It looks like we will have a great event with the participation of ostomates from island wide.

Martha Vélez de Nieves – IPP, NCACOA

Asociación de Ostomizados de Puerto Rico
PMB-14 P.O. BOX 6022, Carolina, PR 00984-6022

Tel: (787) 762-3314

Email: ostomizadospr@yahoo.com

Web: www.geocities.com/ostomizadospr (just updated)

OAT & T



OSTOMY ASSOCIATION
OF TRINIDAD & TOBAGO

OSTOMY ASSOCIATION OF TRINIDAD & TOBAGO

The OAT&T is a registered non-profit organization, which was re- formed on 7th August 1999 to assist and counsel members in Ostomy care.

The association also accepts persons with different types of colon diseases such as Ulcerative Colitis and Crohn's Disease and Cancer. Presently our membership is 45 persons. Ostomates are persons

who have ostomy surgery and wear special appliances or pouches on their abdomen to collect urine or stool.

The following are the association's objectives:

- Educating and Visiting members and their families
- Counseling patients prior to surgery
- Caring and management of Ostomy after surgery
- Assisting members with donated pouches from Friends Of Ostomy Worldwide

Our aim for 2005-2006 is to visit patients in remote areas who use plastic bags and other unhealthy habits because they cannot afford the appliances and this causes skin irritation, bleeding and pain.

Activities for year October 2005 to September 2006 is as follows:

We meet every third Saturday monthly at U.W.I. Works Department, Agostini Street, St Augustine at 3.00 pm where we encourage members that life goes on with an Ostomy, because after surgery patients often seclude themselves and refuse to accept life and prefer to die because of lack of funds to purchase pouches and receive counseling.

completed are:

- Ostomy Management and Home Care
- Diet and Ostomy
- Open discussion with Doctors
- Bird Flu
- Beauty and how to dress after ostomy surgery
- Nurse with film and videotapes on Ostomy care
- Handing out of donated supplies from Friends of Ostomy Worldwide to members
- We hand out brochures and other educational material to members.

Other activities and accomplishments:

- Christmas Party - we held our 7th Annual Christmas dinner at a restaurant; 32 persons attended.
- 8th Annual Family Day May 2006 – we celebrated our family day at the Mayaro beach, 25 persons attended.
- The Executive Committee held 10 lecture sessions at San Fernando and Port Of Spain Hospitals with Care Givers.
- We have monthly visits to Hospitals and Nursing Homes.
- We have placed articles in Newspapers on Ostomy care.
- We are planning for our 1st Ostomy Day in October 2006.

Thanking your for your kind cooperation and support.
Sincerely,

CHARMAINE MARAJ-EDWARDS, Secretary
P.O. BAG #53
BELMONT. TRINIDAD W.I.
Tel: 669-6229, 782-4431, 633-2848

BERMUDA OSTOMY ASSOCIATION

Seen in the news:

Royal Gazette (Bermuda) - March 15

The Bermuda TB, Cancer & Health Association presents "Strike Back at Colorectal Cancer at 7 p.m. at the Bermuda Underwater Exploration Institute with Dr. Richard Swanson, associate surgeon at Brigham & Women's Hospital, Boston and **Lynn John, Secretary of the Bermuda Ostomy Association**. Health information and door prizes and refreshments will be served.



OSTOMY ASSOCIATION OF MEXICO

In October 2005 we opened a wound care and Ostomy Center in the ABC Hospital in Mexico City. At the inaugural event of the opening of this center, I was given a special award and recognition by the hospital for many years of work there in ostomy patient care as well as cancer support. ABC stands for American British Cowdray Hospital in Mexico City, where we held the first NCACOA Regional meeting.

Sheila Carral
President



UNITED STATES



ONE ASSOCIATION CLOSES:

As you may be aware, the UOA Board of Directors announced in May 2005 that it was ceasing operations on September 30, 2005. Membership decline, increasing operational expenses and projected budget deficit were cited as reasons for this action. Although the UOA closed its doors last October, it remains as a legal entity until its assets have been disposed of in accordance with the US Federal tax laws and those of the States of New York and California. It is anticipated that the disposition of assets will occur before September 30, 2006.

UOA continues to maintain its website, www.uoa.org although the data displayed is not current. All of the Care Manuals, most also in Spanish, are posted on the website and can be downloaded, without fee or formal permission, by anyone who wishes to have a copy. These manuals, long a highly regarded resource for new ostomates, include Colostomy - A Guide, Ileostomy - A Guide, and Urostomy - A Guide. Although the UOA website will cease to exist after September 30, 2006, these manuals will still be available on the UOAA website.

A NEW ASSOCIATION OPENS:

Upon the announcement that UOA was "going out of business", steps were taken by Ken Aukett and a Steering Committee (consisting on Julielyn Gibbons, Dave Rudzin, Ginnie Kasten, Charlie Grotevant and Ron Tittlebaum) to form a new organization. The United Ostomy Associations of America, or UOAA, is a non-profit association, incorporated in the State of New Jersey, and recognized by the US Federal Government as a tax-exempt charity.

The driving factors behind the organization of UOAA were:

- 1) the need for a national organization to maintain an effective presence when advocating for ostomy patient's rights with Federal and State Government Agencies; and,
- 2) to provide an infrastructure for linking the local ostomy groups nationwide to promote solidarity.

To date 224 ostomy support groups have affiliated with UOAA. Included in this total are the Ostomy Associations in Bermuda and Puerto Rico. Thank you, Bermuda and Puerto Rico, for the vote of confidence!

UOAA, an association of local ostomy support groups and associations, hospital based ET-led ostomy patient groups, and "virtual" network support groups (Teen, Young Adult, Parents, 30+, Continent Diversion, Gay and Lesbian), used IOA as a structural model. Like IOA, it is an association of associations. Like IOA, it does not have individual members, but only associations as members. Like IOA, it is directed by volunteers, with only two paid consultants. Like IOA, it operates on a minimized budget. UOAA's current operational budget is 80% less than UOA's was in 2005.

UOAA's Office Administrator is Joan McGorry, herself an ostomate. She has established UOAA's official contact office

in her home. UOAA's postal address is: P.O. Box 66, Fairview, Tennessee 37062

UOAA was able to acquire UOA's toll free number, a good strategic move since it has nationwide recognition. This "Help Line" number is 800-826-0826. For those calling from outside the US, the contact office telephone number is +615-799-2990.

www.uoaa.org is the address of UOAA's comprehensive website, which features local support group contact information, organizational data, links to many key websites, basic ostomy information and user-friendly discussion boards for general questions and sharing of information, and specific boards for teens, young adults and those with continent diversions. Our website was designed and is maintained by Bob Baumel on a contractual basis. Bob was the former webmaster for UOA.

For a regular source of ostomy information and inspiration, UOAA contracted with Ian Settlemire to publish a quarterly magazine entitled, **The Phoenix**. Four (4) issues have been published to date. Domestic and foreign subscription information can be obtained from the UOAA website or by communicating with Ian at P.O. Box 3605, Mission Viejo, California 92690. Funds obtained from **The Phoenix** subscription fees serve as UOAA's primary source of revenue.

An election of Officers and Directors will be held this Fall. Each affiliated support group will have one vote for each member they have reported to UOAA. The new Management BoD will take office January 1, 2007. Officers will serve a 3-year term. The office of President Elect has been established, and there will be no Immediate Past President position. It is believed that this will ensure a seamless leadership transition, a feature deemed important in maintaining the organization's planning initiatives and continuity.

UOAA will hold its first National Conference on August 15-19, 2007 at the Lincolnshire Marriott resort in suburban Chicago. The dates for this conference were agreed to with the Marriott, unfortunately, prior to the IOA's announcement of its August dates for the 12th World Congress in Puerto Rico.

UOAA has submitted an application for membership in NCACOA. Since UOAA has less than the 500 minimum members, it will have only one vote in the Regional proceedings and at the World Congress. UOAA welcomes the opportunity to participate in the global theater of National Ostomy Support Organizations and trusts that its inputs on quality of life issues will help to further the cause of ostomy rehabilitation worldwide.

Prepared by Ken Aukett, President, United Ostomy Associations of America. *A report request was sent to UOA President Dean Arnold, but UOA has not responded to date.*

NCACOA FINANCIAL STATUS REPORT

The financial status of the Region was cut deeply when the UOA closed. They were by far the largest dues-payer, and one of the most reliable.

Total dues ANTICIPATED per year:

with the UOA: nearly 6,000 Swiss Francs
without the UOA: less than 2,500 Swiss Francs

Total dues ACTUALLY RECEIVED per year:

With the UOA: about 5,000 Swiss Francs
Without the UOA: just 1,500 Swiss Francs

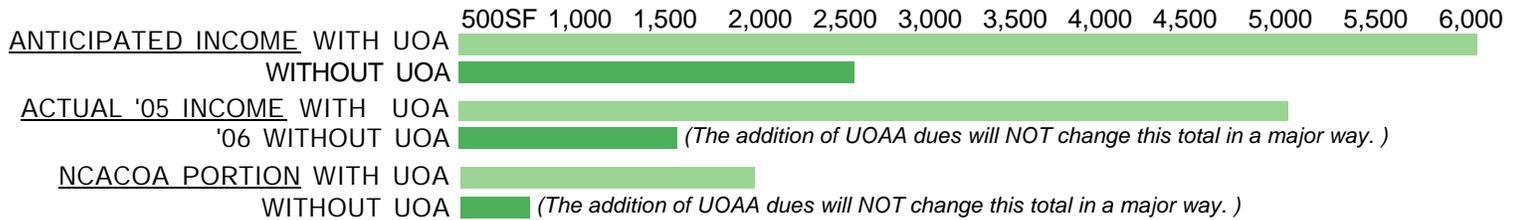
NCACOA's annual share (40%) of dues actually paid:

With the UOA: about 2,000 Swiss Francs
Without the UOA: only 600 Swiss Francs

It may be easier to comprehend by seeing the chart below.

Dues notices have gone out for 2006, but so far only 3 member associations have paid. The NCACOA will need our portion of the funds in order to help pay expenses at the IOA World Congress, so I encourage you to make arrangements as soon as possible to pay your IOA dues.

Please ask about the Maria Siegl Friendship Fund – it can help you pay your association's dues, so that your group and members will continue to receive the benefits of IOA and NCACOA membership.



IOA WEBSITE INQUIRIES:

The website of the IOA provides a method for site visitors to ask questions to IOA regional and international leaders. Since October of 2004, the Regional President has responded to 90 such inquiries received through this communication method. The questions come from patients, families and nurses, seeking all types of help, from supplies, to support groups, to planned travel within the NCACOA, to whether flu shots are needed. As might be expected from the pattern of computer ownership and Internet usage, most inquiries are from residents of the US and Canada. Inquirers are directed to the appropriate national association for local assistance. You may view this 'web-form' at <http://www.ostomyinternational.org/information.htm> .

to support groups, to planned travel within the NCACOA, to whether flu shots are needed. As might be expected from the pattern of computer ownership and Internet usage, most inquiries are from residents of the US and Canada. Inquirers are directed to the appropriate national association for local assistance. You may view this 'web-form' at <http://www.ostomyinternational.org/information.htm> .

Live Life to the Full WORLD OSTOMY DAY™ Will be observed 7 OCTOBER 2000

Please tell our NCACOA Liaison of plans your association has to observe this day and spread good news to all in your home country: Sheelah Zapf at sheelah@telusplanet.net



NCACOA MAP & MEMBERS



FOLLOW US TO FAJARDO !!

12TH WORLD CONGRESS

7 to 12 AUGUST 2007

**in lush, tropical PUERTO RICO -
the Fajardo Inn, Puerto Real, Puerto Rico**

www.fajardoinn.com



- NCACOA Regional Meeting & elections
- meet ostomates from around the world
- elect IOA officers at World Council
- visit exhibits of all major manufacturers
- attend workshops on many topics of interest to association leaders
- tour Old San Juan, tropical beaches, a rainforest, plus more