

Editor: Stuart Schaefer
ioatodayeditor@ostomyinternational.org**Associate Editor:** Di Bracken
vicepresident@ostomyinternational.org**April 2003**
Volume 2 Issue 2

In this issue of IOA TODAY you will find the regional reports as presented at the executive meeting in Wokingham England in March 2003.
(Please note: Contact the IOA Vice President: ioavicepresident@ostomyinternational.org before reprinting any article from this newsletter.)



IOA President's Report

By Heinz Wolff
ioapresident@ostomyinternational.org

SARS VIRUS CAUSES 2003 CONGRESS TO BE CANCELED

Dear Friends



Time flies and here we are again with a new issue of our Magazine. Although a relatively short time has passed since our last issue a lot of things have happened - pleasant and unpleasant. I will start with the more pleasant.

The Executive Committee had a Meeting in March in England in which for the first time we had the

pleasure of hosting the President of the WCET and a Senior Member of Industry. The aim of this triangular meeting was to find out a successful and practical way in which all three parties could work together for a successful, economical and practical way. Up to now unfortunately this was not the case. WCET and IOA were working miles apart yet aiming for the same goal which is the benefit for the ostomy patients. Now we have found out that there are many ways in which through co-operation and understanding for each other we can work together and achieve much better results. I hope that this co-operation will last and all parties will benefit.

And now to the unpleasant and regretful news. The Executive Committee had to come to a very difficult decision and that is to cancel the World Congress in Bangkok in 2003. I am sure that this

Continued on page 2



From the IOA Vice President Di Bracken

ioavicepresident@ostomyinternational.org

Dear Friends of IOA,

This has been a very difficult time for the Executive Council of IOA as Heinz has told you. Making the decision to cancel the World Congress in Bangkok was a heart wrenching decision and, naturally, there will be many implications following this decision. The current Executive Council will remain in place for no longer than one year; elections must take place by the end of one year to ensure the integrity of the organization.

(Continued from page 1)

When the Executive Council met at the Executive/Strategic Planning meeting in Wokingham, England last month we were making the final preparations to the programme for the Congress; little thinking that SARS would soon become a major concern.



Di Bracken --- Heinz Wolff --- Sandra Smits

As you are all aware, the business of the organization is conducted at these meetings and I would like to highlight some of the major decisions for you.

IOA Contact Office

Heinz reported that financial support for the British Colostomy Association is changing and they can no longer continue to act as the contact office for IOA. They will do so until the end of October so IOA can make other arrangements.

This is a major concern for IOA and we would value any input regarding this matter.

INTERNATIONAL UNION AGAINST CANCER (UICC)

We have paid the dues of US\$1000.00 to retain our Associate Membership in the organization. John Cardosa, the past president of the Asian region, is our contact with UICC.

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Editor Notes

As of this issue there are 1293 receiving the IOA Today. That is an increase of nearly 100 since the last issue. The newsletter is being sent via the Internet to over 70 countries throughout the world.

Don't forget to visit the IOA Discussion Forum where you will find people posting and answering Ostomy related questions:
www.ostomyinternational.org



Heinz Wolff & Sandra Smits

Continued from page 1

will come as a great shock to many of our members, and I know that many of us were already booking and hoping to meet old friends again. This was the first time that the 20/40 Group was to be with us at the General

If you are a Patron Member, we will be in touch with you as soon as we have the pins.

World Ostomy Day IV.

We have received entries from Australia, Brazil, Canada, Iran, Poland, Puerto Rico, Slovakia, Spain, Thailand, and The Czech Republic. Gerry Barry made a number of recommendations that were noted and will be referred to the next administration.

His recommendations were noted and will be referred to the next administration.

Future World Congresses

It was agreed that three bids will be allowed to move forward:

New Zealand

Puerto Rico

Italy

Revision to Chapter Handbook

At the Regional Meeting of NCACOA, Kenneth Aukett and I had the opportunity to meet for a few hours and completely go through the IOA Handbook. A number of changes were made. I presented the changes to the Executive and asked for input and corrections as the Handbook was reviewed. This task was completed.

It was agreed by the Executive Council that Kenneth Aukett be charged with the responsibility of completing the revision of the Handbook and see its completion.

As soon as the Handbook is ready we will let you know.

Please keep watching the Website for further information regarding the World Congress. We will do our best to keep you up to date with the information.

Please be careful as you go about your daily lives. Stay safe and my wish for you all is that you stay healthy.

Di
ioavicepresident@ostomyinternational.org.

Assembly and I was really looking forward to this event

as they are the future leadership of our organization.

As you can well imagine the reason for this unpleasant decision was the SARS disease which is spreading at a terrific rate. We cannot take the chance to let our members travel at this time and the warnings which are put out by the WHO made us come to this final decision. We have also been informed that many of our prospective participants would not be able to get health insurance to this region.

We are hoping to find a new venue within a very short time as according to our Legal Adviser we must have the General Assembly by 2004.

Please follow our website for future information.

With Best Regards
Heinz Wolff
President I.O.A.

Continued from page 1

WORLD OSTOMY REPORT III

This comprehensive report has been completed by Brenda Flanagan. It has been mailed to all member countries and provides detailed information on the status of ostomates around the world. It is a most interesting report. If you are interested in obtaining more information about the report, please contact Brenda at her e mail address: pastpresident@ostomyinternational.org

Chris Has An Ostomy

Congratulations to Sociedade Brasileira Dos Ostimizados (SBO). This association has translated Chris Has an Ostomy into Portuguese. Ten thousand copies have been printed. If you are interested in obtaining a copy, please contact the Brazilians at sbo@olimpo.com.br

Patron Membership Pin

I presented a proposal from Kenneth Aukett regarding the design, cost and supplier for the IOA Patron Membership pin. It was agreed that the pins would be ordered. Design: IOA logo the shade of green that appears on the logo on the cover of the OI magazine, with a white background. The word "Patron" will be either a dark green or black.



www.ostomyinternational.org

ALADO REPORT



Heinz Wolff & Maureen Flynn

Peru: Only recently they have acknowledged receipt of the mail. Say they will be sending information shortly.

VIII ALADO Regional Meeting

To be held in Buenos Aires 3 and 4 May 2003. Basically it is to have elections and talk about the future of ALADO.

The situation until my departure:
Brazil, Bolivia and Colombia: confirmed that they could attend
Peru: have not confirmed
Chile: still evaluating whether to travel or not.
Paraguay: to be confirmed as observer

As I've mentioned before, this meeting will not take place unless we have the confirmed attendance of at least two other countries besides Brazil, Colombia and Argentina.

Maureen Flynn
President

London Meeting - MARCH 2003

COUNTRY REPORTS AND NEWS

Only a few counties have sent me their reports or newsletters.

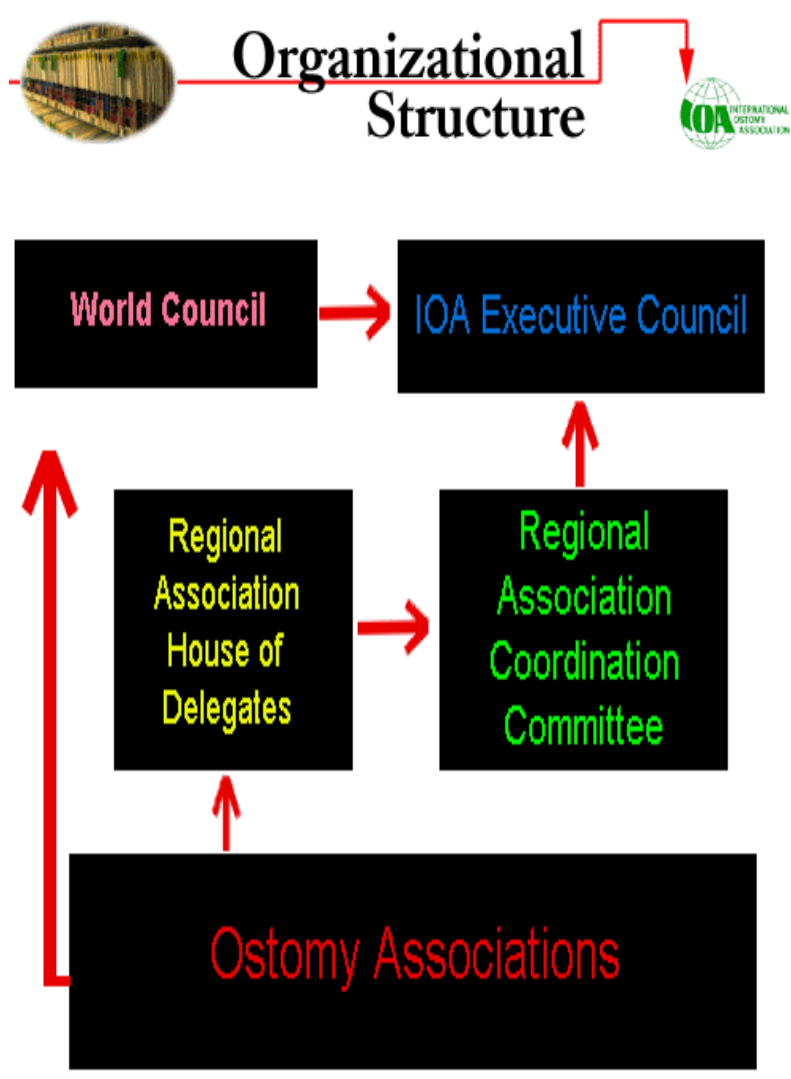
Brazil: > 2002 report of activities available in Portuguese.
> They are holding a Congress in September 18th to 21st 2003.
> They have printed "Chris has an ostomy" in Portuguese - 10.000 copies
> They mention that they have obtained two tickets to travel to Bangkok, one will be used by the 20/40 group. They ask for funding of other expenses.

Chile: > They now have 2.680 members of which many depend on the association for their supply of pouches.
> They continue with their monthly meeting and workshops.
> They have a Psychologist and an ET working with them.
> Every year, in September and December they organize social activities.

Argentina: > LACIU is forming a Federation together with two associations in the interior of the country. Besides it continues with its usual activity.

Bolivia: said they were forwarding information but I did not receive it.

Colombia: OVA (Valle del Cauca) : sent a newsletter
ACDO (Bogotá):
> sent a report in Spanish - they continue with their usual activities and are working together with Convatec and Coloplast.
> they are seeking for funding to be able to attend the congress in Bangkok
(cost of the ticket U\$ 3.000.-)



EOA REPORT 2002

Membership

At present EOA has 43 member associations (32 full members and 11 associate members).

During 2002 two new associations applied for full membership: Turkish Ostomy Surgery Association (Çukurova, Turkey) and Federation of Ostomates and Incontinent Persons "ONLUS" (Milan, Italy). The latter association is the second Italian association. It is organised and headed by ostomates. The Italian organisation submitted already the full text of the Constitution, Turkish Association sent only a report describing the activities and structure of the organisation. It is expected that both these associations could become the membership at the 11th IOA Congress in Bangkok, provided they fulfil all required formalities and pay their dues.

Payment of membership dues

The payment has improved in 2002 as compared with previous years. The IOA Treasurer reported that 8 countries have not paid. Six of them are small organisations from economically weak regions. The only problematic association is the Algerian one. It has not paid dues for more than three years and both EOA and IOA officers have been unable to make any contacts with it.

Communication

It was rather difficult to maintain communication with all EOA members. The associations do not report changes in contact data (even though they were repeatedly asked to do so promptly) and to keep the Directory up-to-date requires thus a lot of detective work.

EOA publishes a *Newsletter* appearing 3 to 4-times a year, which offers a platform for information exchange. Only a few associations used it, however.

Activities of EOA

In 2002 the EOA Co-ordination Committee held only one meeting, which took place in Canterbury in November. The main agenda item discussed was the preparation of the 11th EOA Congress. The Congress will be held in Porto, Portugal from 29th September to 3rd October 2004.

The largest action organised in 2002 in co-operation with the Lithuanian Ostomate Association was the 4th Meeting of Ostomate Associations from Central and Eastern Europe in Kaunas, Lithuania, from 31st May to 3rd June. Nine countries participated in this Meeting, which was mostly devoted solving practical problems with appliance supply and activities of ostomate associations. The Meeting was connected with a 7th Central European Congress of Coloproctology and Viscerosynthesis and thus there was a possibility to establish contacts with physicians.

Full report of this Meeting was published in *IOA Today* 2002/3.

For May 2003 German ILCO prepares an EOA Advocacy Workshop (Frankfurt/M., 1st-4th May). The Workshop is designed for ostomate associations from countries of the European Union and will map the social situation of European ostomates and give information on Advocacy Management in EU. The Workshop is in particular important for countries joining EU in 2004.

International activities of member Associations

As mentioned above, the CC has only limited information on activities of member Associations, which has been collected in most cases indirectly. The difficult situation with the supply of stoma appliances in several countries of Eastern and Southern Europe is being solved by sending surplus

appliances by associations which have either patron or partner relationship with ostomates in countries needing help.

For several years German ILCO delivers appliances to Ukraine, either to Kiev or Lviv organisations. Israel supports the Odessa organisation. British Ileostomy and Internal Pouch Support Groups helps to build ostomate organisations in Romania. A national meeting of ostomates, surgeons and stoma therapists should take place under auspices of ia in Sinaia, Romania, in the middle of May. It is hoped that local groups will found a national association during this meeting. Norilco has partner relationship with ASSCOL, the ostomate association in St. Petersburg in Russia. Besides sending material help they organised a course in St. Petersburg in June 2002, in which ostomates, physicians and nurses participated. (The report on Norilco activities appeared in *IOA Today* 2002/3.) It should be also mentioned that the Moscow association, ASTOM, is active as a consultant in Belarus, Ukraine, and other Russian regions, even though it cannot offer any material help.

The Co-ordination Committee asked the economically well situated countries to offer any sort of help, in particular in the Balkan region, but no response has been received.

17 March 2003

Vladimír Kleinwächter
EOA President



Harikesh Buch & Vladimír Kleinwächter



Discussion
Forum



<http://www.ostomyinternational.org/forums.htm>

NCACOA COUNTRY REPORT

By: Martha Velez de Nieves, President

The North America, Central America & Caribbean Ostomy Region celebrated our Regional Meeting from January 23-26, 2003 in Panama City, Panama.

We discussed many important matters and made decisions that will certainly improve our relations. Countries present were Canada, Mexico, Panama, Puerto Rico & the United States. We had a very successful meeting. Our next Regional Meeting will be held one day prior to the World Council in Bangkok, Thailand on October, 2003. In Bangkok, we will have elections for the EC of NCACOA.

Cuba has been accepted as a provisional member of NCACOA, and the application will be forwarded to IOA, and presented for approval by the IOA House of Delegates. Several NCACOA members in memory of Maria Siegl will pay their membership dues. Cuba has informed, that in order to be able to attend the IOA World Congress, they need a letter of invitation from IOA President.

Dr. Kevin McHugh has been appointed as the 20/40 Focus delegate to represent our region at the World Congress meeting in Bangkok. I would like to point out that only Canada submitted a candidate. The other members of our region didn't have a suitable candidate. There are many people in our region that are not fluent in English, and also the economic situation is not the best.

I'm very pleased to announce that the UOA Website has been redesigned, and has included a Spanish section. There are many Latinos in the United States. I'm sure this will also help the other Spanish-speaking people in our region.

The other countries of our region continue doing their work at a normal pace. I have been in contact with Xaman Ek, Hollister Representative in Mexico, and she has informed me of the many other ostomy groups in Mexico. I will make contact with these groups to find out what is their actual situation.

March, 2003

South Pacific Ostomy Association Report

There has been some activity in the South Pacific region, which is the smallest region in IOA where the only member countries are Australia and New Zealand. Australia has not made any progress in establishing communication channels with Ostomates in Papua New Guinea. The one bright hope was a surgeon who subsequently was transferred to one of the outer Islands and as a result contact was lost.

However New Zealand has had far more success I am pleased to report, the Fiji project is progressing. They have had regular contact with a Nurse in Fiji who will start the distance-training program for Stomal Therapists shortly. They have identified another Nurse and have offered her the same opportunity but as yet no reply.

The Fiji Cancer Society is distributing appliances provided by New Zealand and more contacts are being fostered in the hope of making more assistance available.

Australia is not giving up, with various avenues being pursued with Red Cross and Cancer Societies trying assisting.

The Australia Fund

The Australia Fund was established by the Australian Council of Stoma Associations to receive donations by member associations for the benefit of ostomates in developing countries. Since its inception, a total of 13 Associations in Australia have contributed to the Fund. In addition, \$11,400AUD of the \$12,300AUD payment received from the Medical Industries Association of Australia for work done by Associations in providing monthly statistics has been contributed to the Fund. The balance of the Fund as at March 2003 was \$46,645AUD.

In October 2002, a training program in stoma and wound care was conducted in Manila, Philippines, as an adjunct to a conference of the World Council Of Enterostomal Therapists (WCET) Australia. 80 Filipino ETs attended the training session.

Funds to support the presence of Australian stoma therapists to act as trainers for the programme were requested of the Australia Fund via IOA channels. Although it was not seen as appropriate that the Fund should support attendance at the conference proper, considerable potential improvements in the management and treatment of ostomates in the region were seen as a probable outcome of the training program. Accordingly, it was considered that the project fell within the guidelines of management of the Australia Fund, and \$1,180AUD was allocated from the fund to assist to support the attendance of one stomal therapist nurse. A similar amount was provided from IOA funds. A total of 7 Australian nurses attended the conference and were involved in the training.

Peter McQueen
Secretary SPOA



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AFRICAN REGION – UPDATE March 2003

THE NORTHERN AREA

- Algeria — A Member of IOA attached to EOA
- Egypt — An Associate Member of IOA attached to EOA

THE SOUTHERN AREA

- Zimbabwe — A Member of IOA

Sr. R. Mutekedza, ET. Of the Stomal Therapy Clinic in Highlands, Zimbabwe, completed the WOR survey form. In her covering letter she reported:

“Our country is going through a lot of instability at the moment and it has greatly affected the health system.

The Ostomy Association of Zimbabwe has been at the Cancer Centre. Due to unavailability of funds to run it the Cancer Centre could not afford to hold the Ostomy Clinic for us any more. They also depend on donated funds. These have literally dried out in our country.

However we have been accommodated at the Albert Zinn Medical Centre until we are able to buy our own place. The Government does not help the Ostomates in anyway – even with supplying the appliance or education, therefore everything we do is at our own expense.

The report I have given you is all estimates added on to the real figures which I have 7920. Of late I cannot visit the rural areas because I have no truck to access the dirt roads in the rural areas my little car keeps on breaking down.

However two of our major cities are covered because that is where our Stoma therapists are. There are 3 Stoma therapists in the country. We with to thank you for all the dedication you have for the ostomates. We hope that our country will go back to normal then we can be able to help every ostomate. As it stands now it’s a night mare because most of the ostomates go without appliances and proper care.

Thank you for your continued support.”

South Africa

Hermanus

The following is a response I received from Tia Beenhakker.

We seem to have a problem being accepted by surgeons and even companies. Occasionally I get referrals from the hospital, but only after the surgery and the patients are on their way home. Many are the times I also feel like packing in, but then again I meet someone with a problem and get motivated once more. I have tried teamwork with the Cancer Association, but no co-operation there either. They have the products, but will not send me names of patients.

My private nursing business is non-existent. I still help where ever I can but with no financial reimbursement. Not many Medical Aids refund these costs.

Thank you for the wonderful magazine received. I have read it from cover to cover.

Thanks again for keeping in contact. God Bless “

BRENDA FLANAGAN



Asian Region



European Region



North and Central America and Caribbean Ostomy Association



Association Latino Americana de Ostomizados (South American Ostomy Association)



South Pacific Ostomy Association



No Region Currently



BEHIND THE SCENES - 3/1/03:
Your UOA National Team at work.

SUBJECT: January 1, 2003 – February 29, 2003: A brief overview description of the activities of your UOA leadership during this period.

FROM: Ron Tittlebaum, President with Advocacy Section by Linda Aukett

Advocacy and Prevention

People with ostomies in the US who rely on state **Medicaid** programs, (the majority being elderly and disabled low income people) may face difficulties in obtaining sufficient ostomy supplies, with budget shortfalls in nearly every state. UOA is taking action in states such as California, where there have been proposals to remove entire classes of covered services including ostomy supplies. Every UOA member in **California** received a letter asking them to communicate with their elected state officials, to help maintain this critical coverage.

The **Center for Medicare and Medicaid Services (CMS)** in late February announced its final codes and fees for redefined categories of pouches. Much of January and February was spent in discussion between UOA Reimbursement Consultant **Colin Cooke** and the DMERC staff doing the calculations, in order to achieve the most advantageous fees. **Results are mostly positive**, with fee increases outweighing decreases 3 to 1. As compared with the end of 2001, fee increases ranged from 5% to 153% (with an average of 35%), while the small number of decreases ranged from 4% to 7% (averaging 6%). We expect that more dealers will find they are able to accept Medicare assignment, thus helping to reduce the net expense to beneficiaries.

A summary of revised codes and fees has been placed on the Advocacy page (www.uoa.org/advocacy) and distributed to members of the **UOA Distributor's Newsletter** subscription list, by **Linda Aukett, Government Affairs Committee** chairman.

As the result of ongoing discussions with **Ron Burton** of Philadelphia, an agreement has been reached that will make his counseling skills available to UOA callers who need this in-depth interaction. Ron B. is a retired MSW, Ph.D. psychologist with a urostomy, highly skilled and trained in individual support issues. He will present a seminar for Social Workers at the 2003 conference in Las Vegas, and undertake several efforts to help us improve the availability of informed counseling in all parts of the US.

In our campaign to obtain coverage of ostomy supplies by **United Healthcare** for non-Medicare insured individuals, we are supported by the **American Gastroenterological Association (AGA)** and the **Digestive Disease National Coalition (DDNC)**. Happily, UHC has responded to the AGA's overtures, and a teleconference is planned in the near future. UOA will provide data concerning UHC's potential cost exposure. A **Florida state campaign** continues, where UHC is the **ONLY** health insurer that does not cover ostomy supplies. GAC member **Vince Puma** is working closely with Florida

legislative leadership to encourage UHC to restore full coverage of ostomy supplies.

UOA members responded in record numbers to an invitation to represent UOA at the **2003 Public Policy Forum of the Digestive Disease National Coalition**. Past President **Dan Tyrrell** will lead the delegation of ten UOA members who plan to attend this event in Washington, DC in late March. These include GAC members **LeAnne Geurin** and **Sterling Alam**.

Field Service

The fourth of our **Ostomy Education Seminars** cosponsored by UOA and ConvaTec is now scheduled for May 31, 2003 in Philadelphia, PA. Development of a fifth OES is underway.

A follow-up meeting is being planned with the Executive Committee and Area Service Directors to provide an update on the new network vision (see below) and to determine strategies for member and chapter development.

Bobbie Brewer made a visit to New Bern, NC on February 6, 2003 to work with that group in completing the formal chapter affiliation process and to provide UOA with an update.

Strategic Partners

We're now pleased to add **Nu-Hope** and **Byram** to our list of ostomy suppliers who will insert a UOA membership application in their publications. They join **ConvaTec**, **Hollister** and **Coloplast** who will also support UOA through their hospital discharge kits.

We are continuing our dialogues with **WOCN** and **CCFA** about attending each others conferences and trading articles in our journals. In addition **Ann Favreau** and **Bobbie Brewer** submitted a proposal for the **WOCN** Conference in Cincinnati in June. Titled **A Carepath to Ostomy Rehabilitation**, it was selected for a poster session.

Ron attended a regional meeting of the **International Ostomy Association** in Panama City, Panama, January 23 – 25, 2003. IOA subdivides into regions and we belong to the North and Central America and Caribbean Ostomy Association or **NCACOA**. Although past UOA leadership such as **Ken and Linda Aukett** and **Marilyn Mau** have remained very active in IOA, recently UOA per se has not. This meeting was therefore a great introduction for this administration into the ostomy service and supply issues beyond our own borders. In many ways, we have no idea how well off we are. At this meeting **Cuba** was provisionally admitted into NCACOA and they will be proposed for IOA membership at the upcoming IOA world meeting in Thailand in October.

UOA Networks.

Following up on their November phone call, Ron met with **Bill Johnson**, founder of the outstanding web page, **j-pouch.org** on January 30 about forging a closer working relationship. We have already established reciprocal links to our web pages and j-pouch.org has agreed to post our key announcements. **Dave Hirschhorn** of our Continent Diversions Network, who also hosts the j-pouch.org chat room was also at this meeting. We have also agreed to host a meeting for their members at our Las Vegas conference. Dave will help coordinate this.

As a result of the **Network Task Force** meeting in Chicago on December 8 and 9, we have now developed a new strategy for allowing members of one network to participate in the benefits of other networks. Chapter members can also enjoy these same benefits. The strategy also defines the opportunities available to network leaders to help them build their benefits and membership. This plan has been submitted to the UOA Board of Directors for discussion at their March 2003 meeting. We now have six networks in operation, **Parents, Teens, Young Adults, Thirty Plus, Continent Diversions and Gay and Lesbian Ostomates**. As of this writing others are being considered.

One of the premises and goals behind the establishment of our Youth Networks was to create leadership opportunities in UOA for younger ostomates. Great examples of this are **Monica Sagastume and Kate Markwith, Program and Promotions** chairs respectively for the **Young Adult Conference**. Both are also currently Youth Rally campers. Equally exciting, the following Youth Rally campers, past campers and councilors will be speakers at YAC; **Jason Brill, Bob Heitker, Juel Cooper, Abby Ryan, Julielyn Gibbons, Ana Gimlen, Tom Sage, Tom Exler, and Zack Walker**.

Similarly the leadership of the **Teen Network** is councilor **Jude Ebbinghaus** and campers **Cheryl Ebbinghaus** and **Brittany Sherman**. As part of the Teen Network start-up, in February **Cheryl and Jude** conducted the first ever UOA survey of potential teenage members developing great insights into what services should be offered.

Income Development

With the strong backing of the central office team of Director of Development **Roger Rustad**, E.D. **Nancy Italia** and our newest hire, **Lori Velasco**, the UOA **Long Range Income Development Committee** (LRIDC) is now becoming productive on many new fronts. We have now been advised that we will be receiving a **bequest** in excess of \$60,000 for our **Permanent Memorial Endowment Fund or PMEF** from the estate of a deceased member in New Jersey. This is in addition to a \$22,000 bequest from Florida previously received by UOA in December.

The **Bristol Myers Squibb Foundation** has now confirmed that we will receive a second **grant**, this one directed at helping us develop our fund raising strategies still further. In addition we have already received two grants totaling \$7,500 for the Youth Rally.

As a result of our Corporate Partner program, the **Young Adult Conference** to be held in St. Paul on July 17 – 19, 2003 now has three Level 1 sponsors of \$5,000 each; **ConvaTec, Hollister and Coloplast**, and three Level 2 sponsors; **Nu-Hope, Cymed and Byram**.

Our **ebay** auctions of Thomas Mangelson prints has now generated sales of over 200 prints and \$22,000.

Launched with an ad in the winter OQ, we have received donations of four vehicles, one of which will also be sold through **ebay** and one boat.

The UOA leadership giving “**Call Team**” is now in place under new leaders **Marilynn Glen and Mike Carlson**, and mentored by our venerable **Cy Smith**. Starting in mid spring the 22 member call team will be directly and personally contacting approximately 180 individuals for donations. Last year this program yielded over \$35,000.

Conferences and Events

Mary Jane Wolfe and **Ken Aukett** and **JoAnne Sisco** and **Vickie Weaver**, the respective committee leaders have now made site visits and selections for the 2004 National Conference and the 2004 Youth Rally. Assuming UOA Board of Director approval for both, the **National Conference** will be held at the **Galt House Hotel in Louisville, KY** and the **Youth Rally** will be at **Chapman University in Orange County, CA**.

The programs for this years **National Conference** and for the **Young Adult Conference** have now been posted on the UOA web page, www.uoa.org. The National Conference program has been developed to include specific program “tracks” for **Parents of Ostomy Children, Young Adults, Continent Diversion** individuals and other groups. The goal is to make the conference much more attractive and meaningful to these groups. The “track” schedules will be listed shortly on the web page. The joint CDN/j-pouch.org track will be a great test for this concept.



41st National Conference
United Ostomy Association, Inc.
August 10-13, 2003 • Las Vegas



FROM THE UNITED OSTOMY ASSOCIATION OF CANADA

President, Lorne Aronson

It was my distinct pleasure along with my wife Louise to attend the general meeting of the Belleville and district Ostomy association. It is a mere two hours from our home and the weather was very co-operative for us to get there in ample time.

We were warmly greeted by Gerry Putman and his wife Bawn (a members of the Spouses and Significant Others Committee). If you were at the conference in Halifax last year you might remember, they gave a session on Tai Chi, they are both teachers of the art. Gerry is the President of the Belleville Chapter, while Bawn is involved nationally with the Spouses and Significant Others Committee.

I addressed about 30 people. I presented some of the ideas and some of the things currently on the go such as the Youth Camp Video, the 20/40 social get-together, the Spouses and Significant Others etc...

I answered questions on these and other topics. One of these questions posed to me was software. Was it available for chapters to improve their local newsletter? I told Paul Aubin (the Newsletter Editor) that I would address this type of question at our strategic plan meeting. This is a question of service to the chapters that indeed is on our agenda.

The Chapter is involved with a team that will participate in a The Relay for Life, a fundraiser for the Cancer Society in Belleville June 27 and 28th. They are producing hats with the UOAC Logo on them to identify themselves as participants in the walk. They were also asked to participate in the Crohn's and Colitis fundraiser the Wheel N'Heel-athon June 7th.

My wife was asked by one of the members if the Spouses could get more involved with chapter organizational functions. The comment of the questioner was to make the point that often times the person who has had the surgery cannot effectively participate with the leadership roles in the chapter, due to ongoing health concerns. The answer was that indeed the SASO committee encourages spouse or significant other or family members to take a leadership role in their local chapter. Louise gave Bawn the pamphlets of the SASO Committee.

One of the things that I did come away with from this meeting was, we have a very vibrant and active Chapter in Belleville! Gerry is to be congratulated on his great leadership of this association!

I will be attending the Strategic and Executive Committee meeting being held at the end of the month April 25,26 27. A report by the Strategic planning Chair (Vice President, Pat Cimmeck) and the Chair of the Executive Committee(that would be me) will report in the May Connection of some of the results. Remember all recommendations by any committee MUST be presented to a FULL Board meeting and voted on before being implemented.

Lorne

"Up Coming IOA Events"



Travel Warnings & Consular Information Sheets:

http://travel.state.gov/travel_warnings.html

Can I take it with me when I travel Rev 11/21/02:

http://www.ostomyinternational.org/Travel/Permitted_Prohibited.pdf

You will need the **FREE Adobe Reader** which maybe downloaded here:

<http://www.adobe.com/products/acrobat/readstep2.html> to view.

On-line Currency Converter: <http://www.amari.com/tools/currency.asp>

FACING THE CHALLENGE ASHBURTON

New Zealand Ostomy Societies

8th – 10th August 2003

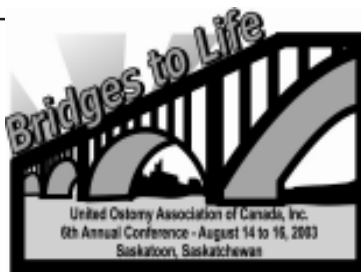
Canterbury Ostomy Society

Further information available from either

Jill Newton Ph/Fax (0064) 03 308 1419 or e mail

newtj@actrix.gen.nz

Barbara Summerfield Ph (0064) 03 308 5471



Wondering what the 6th annual UOA Canada Conference “Bridges to Life” has to offer?

WE'RE EDUCATIONAL... you'll enjoy interesting and informative sessions on...

- What naturopathy has to offer ostomates
- Getting stroke smart
- The benefits of holistic nutrition for ostomates
- Coping with changes in body image
- The truth about nutritional supplements
- Doctors with a social conscience
- Relaxing through nature and photography
- The wisdom of enterostomal therapists
- Endoscopy procedures and ostomates
- Common stoma problems
- The future of medicare in Canada
- Sexuality, dating and relationships

In addition we have:

- **EXHIBITORS** with the latest in products of interest to ostomates
- The **STOMA CLINIC** - which provides the opportunity to consult privately with an E.T.
- **RAP SESSIONS** – a chance to talk with a group who share your specific surgical experience
- **VISITOR TRAINING**

20/40 DELEGATES can look forward to...

- volleyball in the hotel gardens
- a pub crawl
- spending time with people who share their unique concerns and experiences
- session on changes in body image and sexuality

SPOUSES and SIGNIFICANT OTHERS will enjoy ...

- their own rap session
- a walking and shopping tour of the historic Broadway area
- a tour “Behind the Scenes” of the historic Delta Bessborough

WE'RE SOCIAL...

The fun starts Wednesday night with “**A Taste of Saskatoon**”. Enjoy food, live prairie entertainment, a fashion show of clothing designed for ostomates, and a chance to meet other conference delegates.

(Included in registration fee)

Thursday evening is **Coloplast Night**. Spend an hour enjoying cocktails and appetizers on **Boomtown**, a living recreation of Main Street Saskatoon in 1910. Enjoy an excellent buffet supper followed by entertainment by comedians/illusionists Black Salt and Brenda Q. (Included in registration fee)

Friday is **Convatec Night**. Enjoy the banquet and join ostomates from across Canada in congratulating this year's recipient of the Renaissance Award for his/her achievements and contributions to their community following ostomy surgery. Stay for more entertainment! (Included in registration fee)

Wrap up your conference with the **Farewell Banquet and Dance**. Following the banquet celebrate the presentation of our UOA Canada Awards. Stay and dance the night away! Supported in part by Hollister.

(Additional charges apply)

Detailed hotel and program information as well as registration forms will be available in the next issue of *Ostomy Canada*.

ONE OF OUR OWN IS HONOURED

The Intelligent Beauty Award, in its 10th edition, celebrated this year, the inner essence of each one of the women who were selected by "Elizabeth Arden" and their magazine: "Imagen". Martha, president of the NCACOA region, was one of the ladies selected for her commitment to those who have ostomies. The following is the tribute paid to Martha. Congratulations Martha; we are pleased to have you on the IOA team.

MARTHA VELEZ DE NIEVES

Brave until weariness (or tiredness) and even after, she gets up every morning ready to perform her faithful commitment with her life since



she has been given a second chance to live. Martha Velez de Nieves, a fighter among fighters, she is a cancer survivor, and among those who had the same experience, she is considered a true champion or hero.

Her life started in Santurce, and followed a normal course of achievements, reaching her goals, love at her door, arrival of children, and many satisfactions and triumphs in her professional career. This is a story quite similar to any other story, until, she found out that she had cancer, and had to undergo a permanent ostomy surgery, that would mutilate her body, but that would save her life.

At that time, Martha used to work with The Emerson Group, in specialized publications, after 22 years of service with The Quaker Oats Company, where she started as an Executive Secretary and became later the Office Manager.

One of the decisions that Martha made was to quit working, although what she really did was to substitute one work for another. At present, she works intensively as a volunteer of Asociation de Ostomizados de Puerto Rico, which she presides. Her efforts, and work at the

association are similar to her efforts and her devotion as President of the North America, Central America & Caribbean Region of the International Ostomy Association. Martha has traveled a lot to learn how ostomates live in different parts of the world.

She was selected National Ambassador of the American Cancer Society to represent more than 45,000 cancer survivors of our island; in the first and great event "Celebration on the Hill" at Washington, DC. She was also awarded with the "Coloplast Merit Award" in 1996 for the best celebration of World Ostomy Day competing with 67 different countries. In 2002, she achieved the second place of this same award. She received the "Gladys Anglada Award", given by the American Cancer Society for outstanding volunteer services. She has also been selected together with her husband to receive the "Red Gala Award", given to honor cancer survivors. She has a great list of achievements. She represents the select group of women that we honor in Women's Week.

"My work as a volunteer is of great satisfaction and pride. You have no idea how I

feel when I see patients smile. Their smile is my best gift, and it is also the road to their rehabilitation. If I achieved this, they can also do it." She said. The person, who speaks, is one who has suffered the same terrible moments of fear and despair with the threat of a mortal disease and the reality of a mutilated body. But, the person who speaks is also someone who was able to fly over the ashes of disease and live again, while singing a beautiful hymn to life. A very special woman whose condition has turned into her mission. "I shall not rest until, I can attain that the whole world knows what an ostomate is, and not reject them, and also that all the medical insurance plans and our local government health insurance, will supply the basic equipment required by an ostomate in order to reach their rehabilitation." she added.

In the meantime, she continues with her personal crusade, which is a fountain of inspiration to others. An active, beautiful, and very well dressed lady, Martha lives a plentiful life, trying not to be worried, to remain calm and in control, and with the support of her husband; who according to her very own words, "is an angel".



IOA
Officers



<http://www.ostomyinternational.org/officers.htm>

THE BACKGROUND HISTORY OF INTERNATIONAL STOMA CARE ADVISORY PROGRAMME (ISCAP)

PILOT PROGRAMMES

At the initial planning stage it was recognized that ISCAP would have to be flexible in order to accommodate variations in approach and take into account the different influences in each country, in each ostomy association and each government, as well as any particular national or local circumstances.

Therefore, before offering ISCAP world-wide, a decision was taken to enlist the support of a small number of ostomy associations with a view to centrally supporting and funding them to pilot ISCAP. The pilot phase was seen as a unique opportunity to evaluate all elements of the initiative including:

- The Concept
- The strategy
- The Tool Kit
- Guiding the wider implementation of the initiative

Incorporating the materials into the pilot programmes provided a valuable opportunity to field test and evaluate the content and presentation, in addition to identifying any omissions which might be helpful to ostomy associations, policy makers and opinion formers.

A decision was taken to use the services of an experienced independent consultant to act as a central co-ordinator for the pilot phase. The consultant would provide a point of contact for queries and ensure that advice and guidance was available as required. It would also enable the sharing and feedback of ideas and experiences of ISCAP in the pilot countries.

The consultant worked on the project from 1995 – 2000 (IOA Congress in Amsterdam).

Ostomy associations in the following countries were invited and agreed to take part in the pilot programmes:

- Dominican Republic
- Egypt
- Mexico
- Peru
- Russia (St. Petersburg)
- Thailand

In January 1997, an induction meeting was held in London to which each ISCAP co-ordinator was invited to attend. The purpose of the meeting was firstly to introduce and work through the Tool Kit and secondly to facilitate sessions on:

- The role of the co-ordinator
- Identifying objectives
- Planning an approach
- Forming a campaign team
- Selection of policy makers and opinion formers
- Contacting, meeting and following through with policy makers and opinion formers.

By the end of February 1997, activity in the pilot countries was underway. They worked through the year on their objectives. In January 1998 a meeting was held in Miami to review the pilot programmes.

Case studies on their activities are available.

MOVING FORWARD

At the end of the pilot programmes it was agreed by IOA and ConvaTec that ISCAP was of considerable value to ostomates

worldwide.

At this stage the whole ISCAP project was handed over to the IOA to be further developed. ConvaTec generously agreed to make an unconditional educational grant to IOA to retain the services of the consultant. They continued to fund the project until April 2000.

Miami was the venue chosen for the next round of training in November 1998. Countries who took part were:

Bulgaria
Colombia
Panama
Philippines

Case Studies are available.

As the project developed and proved to be of great benefit to ostomy associations, it was deemed essential to give serious thought to how IOA would carry on the ISCAP programme once we no longer had the services of a consultant.

It was agreed that there should be one person in each Region to act as ISCAP co-ordinator. Their main functions would be:

- To work closely with the IOA ISCAP Liaison Officer and the Regional President/Regional Executive Committee on:
 - The provision of support and information to Ostomy Associations participating in ISCAP within the region of work
 - The development and implementation of a regional ISCAP monitoring and evaluation programme
 - Regional ISCAP strategic and operational planning
 - The development and implementation of regional ISCAP training programmes.

To assist them in these tasks the consultant and IOA ISCAP Liaison Officer organised a training session to develop some aspects of the desirable skills and all aspects of responsibilities. They also developed a Training Manual for the trainers together with visual aid material..

In April 2000, the services of the Consultant came to an end.

In November 2000, as the IOA ISCAP Co-ordinator, I undertook a training session with representatives from: Indonesia; Nepal; Philippines and Taiwan. This took place at the close of the Asian Ostomy Association's Regional Meeting in Penang.

THE FUTURE FOR ISCAP

The ISCAP project is now joint funded by Industry.

It is now time to set down a new strategy for the future of ISCAP. I think the current World Ostomy Report is an indicator of where help is needed. There are also needs in countries not included in the WOR.



BRENDA FLANAGAN
IOA ISCAP Co-ordinator

For further information about the Iscap project please contact
Brenda Flanagan: pastpresident@ostomyinternational.org.



Very Important Computer Virus Information From IOA

Over the past few months it has been reported by many that they are receiving emails from the **International Ostomy Association** which are not being sent from us. First it was thought that the email addresses were being forged. After doing much research, it has been found that someone or more than one, may have a system that has been infected with a computer virus. They may not even realize their system has been infected. This is becoming a real problem.

What is happening is the system or systems that are infected are sending out emails to anyone on their mailing address book without that person even knowing. The emails may look as though it is coming from the International Ostomy Association, which they are not. It could have different subjects like: "Eager to see you", "Worm Klez.E immunity", "A new game", and others. In many cases it may not even have a message.

Now the question is what can be done about this problem. This is why we are posting this message to all of those who view and use this Forum. We are advising that if you do not have an **Anti Virus program** installed to get one. Both Norton <http://www.symantec.com> and McAfee <http://www.mcafee.com/> offer good Anti Virus programs. If you do have an Anti Virus program installed it would be advised that you run it ASAP. Also make sure you are up to date with the latest Virus Definitions. These change almost daily.

In the mean time you may want to run a **FREE Security Check by Symantec:** <http://security2.norton.com/ssc/?j=1&langid=us&venid=sym&plfid=23&pkj=GURIFIZTYMWP AZTJWUF>. They offer two tests. One is "Scan for Viruses" and the other is "Scan for Security Risks". Both are **FREE CHECKS**. Now in some cases if your system is infected Norton does have some patches that maybe able to be used to remove the virus. However in some cases you may have a system that is so infected the only way to remove the virus will be to reformat your hard drive. This does mean you will lose all information on your system.

A MAJOR virus called: **Klez** virus is also causing many problems. More information about this virus can be found here: <http://securityresponse.symantec.com/avcenter/venc/data/w32.klez.e@mm.html>. You will also find a program that can remove this virus from the above location.

F-Secure - Klez

Explains how this worm works and discusses its "E" and "G" variants.
www.europe.f-secure.com/v-descs/klez.shtml

Latest Virus Advisories: <http://www.antivirus.com/vinfo/> (as of April 30, 2003)

We strongly encourage you to update your scan engine to ensure you are using the best virus protection available.

Free Anti-Virus Protection! AVG 6.0 Free Edition.

http://www.grisoft.com/html/us_index.htm?session=3bd84511c78641d150ad792040b812f

Download, install and use AVG 6.0 Anti-Virus system to reliably protect your computer and data free of charge.

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