Dear Friends:

Our first newsletter of the New Year 2005 has to address the tsunami disaster which has devastated large parts of southern Asia. Naturally we are concerned for all peoples including those of us who have had Ostomy surgery.

It is difficult for us to realize tens of thousands dead, many still missing and millions displaced, with survivors facing the very serious problems that lie ahead. We in IOA have been active in offering help where we can. I have been in touch by e mail with the key ostomy people in the Asian region, particularly Harikesh Buch, President of the Asian region and Past President Dato John Cardosa. They are in touch with the countries in the area and we have been advised to wait until the major relief associations have the situation under control and a clearer picture of what is needed emerges. Our new Relief Coordinator, Arne Holt of the Norwegian Ostomy Association and President of the European Region sprang into action immediately, has been in contact with the Red Cross and the manufacturers of ostomy supplies. Many individual countries have been in contact asking what they can do and we have given the same advice as we were. Wait a while – long term there will be a definite need. IOA is poised and ready to ask countries for help as soon as we find out what is needed.

The new IOA Executive Council has its first full meeting from 4 – 6th November, 2005 in Copenhagen, Denmark at the corporate offices of Coloplast. One of the topics on the agenda will be the organization of ostomy supplies to countries where the need is great. There will be a full report of this meeting in the spring edition of IOA TODAY. A copy of the minutes will be circulated to all country presidents as soon as they are completed.

The Future in Stoma Care depends very much as to where in the world one lives. What is desirable in Western Europe is very different from what is desirable in many Asian countries. IOA still has a great deal of work to do to help developing countries obtain ostomy supplies from their governments. Looking into the future in a scientific manner is something that we do not do very often and this was a tremendous learning opportunity for me as well as being able to address the attendees on the future needs of ostomates.

It was my pleasure to return to Hong Kong in November, a country very near and dear to my heart. I first arrived at Kai Tak airport in 1961, a single lady ready to teach in British Army Schools Overseas. I left almost ten years later with a husband and two children! It was indeed like going home. I was going for a specific reason – to help celebrate the 25th anniversary of the association there. I am pleased to share with some highlights from the celebrations.
This whole 25th Anniversary Symposium was very different in its approach from any other that I have attended and was a learning experience for medical professionals and ostomates as well as an anniversary celebration. A very clever, carefully thought out programme was divided into two main sections

1. From Prevention to Rehabilitation
2. From Self Learn to Mutual Help

The Hong Kong Stoma Association (HKSA) had invited experts and experienced practitioners in the field to share their insights and discuss their experiences in relevant topics. There were 300 people in attendance with ostomates from not only Hong Kong but the following groups from China - the Beijing Stoma Association, the GuangXi Stoma Association, the Guangzhou Stoma Association, the Hangzhou Stoma Association and the Shanghai Stoma Association. There were also ostomates from other Asian countries from the Japan Ostomy Association, from the Ostomy Association of the Philippines, from the Thailand Ostomy Foundation and from the Vietnam Ostomy Association. It was hoped that there would be representation from Taiwan but at the last minute, the representative was unable to attend.

The Hong Kong Cancer Fund was the co-organizer and sponsor of the symposium together with the Hong Kong Enterostomal Therapist Association. Mr CHAN Yiu Kwong, Chairman of the HKSA indicated “that these two organizations have all along supported HKST with financial and professional supports respectively, truly observing the spirit of transdisciplinary collaborations that we advocate in this symposium.”

It was the hope of the organizing committee in this comprehensive collaboration to provide “a training opportunity for health care professionals to equip them with the latest knowledge and skills in ostomy care and rehabilitation, and to enlighten them with the practice of transdisciplinary collaboration in better serving ostomates.”

Day Two of the 25th Anniversary celebrations centered around the ostomate. Opportunities were provided for the various groups taking part in the celebrations to share their experiences and further explore the possibilities to improve the life of fellow ostomates.

Morning Session MANAGING PATIENT SELF HELP ORGANIZATIONS
  - Management Model of Patient Self Help Organizations
  - How to Sustain the Motivation and network of Volunteers
  - The collaboration between Cancer Patient Resources Centre and Patient Self Help Groups in Patient Care
  - How to Develop and Sustain Volunteerism in Self Help Groups
  - Introduce CancerLink Support and Resource Centre, a Service of the Hong Kong Cancer Fund.

This was one of the most interesting sessions I have sat through in regard to this topic. I was truly most impressed with the quality of the speakers and all relating their topics to ostomates. The number of volunteers that are involved in helping with the work of HKST is truly outstanding; many of them are not ostomates but are experts in their field and help the association with definite tasks.

Local and overseas ostomy groups provided information re their particular group. Each group was asked to include the background of the group, activities of the ostomates, collaboration between health care professionals and groups, support network among ostomates.

The closing discussion related to how to strengthen the development of ostomy groups so as to improve the quality of life for ostomates.

The groups from China all reported the same difficulties:

- No fixed funding resources; occasionally there is some help from the government agencies.
- Lack of ostomy supplies.
It is very difficult to organize centralized activities in rural China. Seminars and information exchanges are concentrated in the major cities. Support for the associations is provided by the Hong Kong Stoma Association; also some help comes from hospitals and health care professionals. Many ostomates live in very remote areas and receive no help. These ostomates are sometimes able to get support from overseas helpers and medical personnel. Still there are hundreds of ostomates in this vast area in great need of care and rehabilitation.

- No fixed channels for communication
- Not enough supplies are received to provide a regular supply for the poor ostomates.
- Many members are very young – still in school and university so there is a real concern as to how they can continue their education when they do not have appropriate ostomy supplies. Quote: “This is a very bad situation for the young people and many are very depressed.” There is an urgent need in how to handle this situation.
- Attendance at all meetings is good as people want information
- Supplies from manufacturers are available but are very expensive and only the wealthy can afford them.
- Manufacturers are providing help whenever they can.
- Association rely solely on the good will from the medical doctors, hospital staff and family members.

The ostomy associations are most grateful to the Hong Kong Stoma Association for reaching out to its Chinese counterparts offering help where and when it can.

JAPAN OSTOMY ASSOCIATION reported at the meeting
- As of January 2002, there were 12,000 members in the association with 66 chapters across Japan; at least one chapter in each prefecture.
- In 1977 Invalidity Pension was provided to ostomates until the age of 65 years.
- In 1979 ostomates were recognized as Handicapped persons. Although appliances are readily available across Japan, they are very expensive. Being recognized as handicapped, ostomates can get reimbursement from the government. This reimbursement is subject to how much the FAMILY income is. It is not based on how much the individual ostomate earns but the total income of the household.
- The reimbursement that is allowed for low income households is colostomate/ileostomate 8,000 yen per month; urostomate 13,000 yen per month.
- 1988 the Association was incorporated under the Ministry of Welfare and Labour.
- Seminars are held five to six times a year with between 50 – 100 ostomates attending each seminar. In Tokyo there is always one seminar held for child ostomates.
- Membership is 80% colostomates, 12% ileostomates and the rest urostomates.
- Average age of ostomates in the association is 61 years.
- Recently, the association has been successful in having a public toilet especially designed for ostomates. Currently the association is trying to get more welfare from the government.

OSTOMY ASSOCIATION OF THE PHILIPPINES
- Presently the association has 100 members- 40 of whom are active.
- Most of the members are jobless and as there is no government funding for ostomy equipment, life is very difficult for ostomates.
- Monthly meetings are held with committee meetings also held separately once a month. At the monthly meetings, free ostomy supplies are given out when they are available.
- These supplies come from countries such as Australia, Friends of Ostomates Worldwide USA and the Cancer Society.
- The organization had an enjoyable time celebrating World Ostomy Day.

HONG KONG STOMA ASSOCIATION
- The association is registered as a not for profit organization and receives its funding through membership fees, the Cancer Fund and some support from the manufacturers of ostomy equipment. There are 2000 members with between 70 – 80 regular volunteers.
- Many activities are held throughout the year. There are always sharing sessions for new
ostomates. The association organizes social and entertainment classes to help the ostomate readjust to life with a stoma. Some examples, Tai Chi classes, painting, singing, playing cards and mahjong. (The choir sang to us at the birthday party and often sings at various functions in Hong Kong. The musical director, a non ostomates, is a professor of music at the University of Hong Kong.)

- As part of its outreach programme to their brothers and sisters in China, some members of the association take long journeys to help their fellow ostomates in various parts of China.
- The Association is an active participant in the Asian Region and in IOA always attending the World Congress.
- Currently a major thrust of the organization is to liaise with the pouch manufacturers on behalf of the poor people who cannot afford to buy ostomy equipment.

The Thai Ostomy Foundation and the Ostomy Association of Vietnam was not able to be present during this sharing session but from my individual conversations with the newly elected presidents, I am able to report the following:

The THAI OSTOMY FOUNDATION:
TOF reported a very similar situation to that of mainland China.
- No government support for ostomy appliances
- no regular funding
- ostomates spread across rural areas with little or no medical care.

In Bangkok, the Thai Ostomy Foundation helps its poor ostomates by providing ostomy supplies whenever possible. Support from physicians and ET's is important in the ongoing work of TOF. Newly elected president Sanun Sillapabunleang is an ostomate.

Ostomy Association of Vietnam
Nguyen Trung Tin, MD, president reported that Vietnam is a newly formed organization that needs a great deal of support to help it develop. Again
- No government support for ostomy appliances
- no funding
- ostomates spread across rural areas with little or no medical care.
- Association founded by an ostomate and an ET.

This was a very moving experience for me as I heard these details of what life is like for so many ostomates in China and indeed across Asia. IOA has had little information as to what is happening across the vast nation of China. I think that this is the first time we have knowledge of the truly outstanding, dedicated work of the Hong Hong Stoma Association in its outreach programme. I am humbled by the number of lives touched, and the extent of the work carried out across such a vast territory.

I thought that you would be interested in the following information regarding the number of ET schools in Asia:

<table>
<thead>
<tr>
<th>Country</th>
<th>ET Schools</th>
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</thead>
<tbody>
<tr>
<td>China</td>
<td>2</td>
</tr>
<tr>
<td>Japan</td>
<td>1</td>
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<tr>
<td>Hong Kong</td>
<td>2</td>
</tr>
<tr>
<td>Korea</td>
<td>2</td>
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<tr>
<td>Thailand</td>
<td>3</td>
</tr>
</tbody>
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Please note a more detailed report of my visit to the Hong Kong Stoma Association is to be found in the next edition of the Ostomy International magazine.

As you can see there is much work still to be carried out help ostomates in developing countries, not only in Asia but there is also a great need in South America and Africa. There are countries in Eastern Europe and in the North American region that also need our help so we will have to continue to work together to do the best that we can to help.

WAY TO GO BRAZIL

I do have a major success story to report to you. President Candida Carvalheira reports a major breakthrough in negotiations with the government of Brazil. President Luiz Inácio Lula da Silva and his government has signed into law on December 2nd, 2004 a bill establishing priorities for handicapped people, specifying categories, including as physical deficiency: ostomy. As Candida says,

“We are entitled by law to 72 articles included in his law which as soon as translated we will send you a copy. In the meantime, Brazilian Ostomates have finally received a well-deserved victory after a 20-year struggle.”
Hopefully we will receive a translation of this new law by the spring edition of IOA TODAY so we can all read of the achievements of ABRASO

CONGRATULATIONS ON THIS ACHIEVEMENT!!!
¡¡¡¡¡¡¡¡¡FELICITACIONES POR ESTE LOGRO!!!!!!!

Candida you, and your fellow ostomates in Brazil, are a shining example of what can be achieved if you are determined and prepared to fight for your rights. WELL DONE ABRAZO!!!

Another achievement:
You will find attached the European Newsletter which contains all the European Ostomy News. This newsletter will be published twice a year and will be sent out electronically with IOA TODAY. We have much information for you to digest in this issue! Congratulations to the new editor Efim Krasner and his co workers

Please stay in touch with me and let me know how you are doing.

As this is the first newsletter of a New Year, may I take this opportunity of wishing you peace and contentment in your lives. May 2005 bring you great joy and above all GOOD HEALTH.

PHOTOGRAPHS FROM THE WORLD CONGRESS IN PORTO NEEDED

Do you have a photograph of the BBraun booth at our recent World Congress in Porto? Rania Abi Saad of BBraun is looking for photographs. She took many pictures only to find that there was something wrong with her camera and none of her pictures turned out. If you do have a photograph, please can you scan a copy to her at rania.abi.saad@bbraun.com or send in the mail to

B. Braun Medical SAS
Attention Rania Abi Saad
204 Avenue du Maréchal Juin
F-92107 BOULOGNE Cedex – France

I know that Rania will be delighted to receive any photographs that you may have. Thank you for looking through your photograph collection.

20/40 Focus 2004 – Creating A Better Life
August 28 – 31, 2004

PORTO

With a lot of help from Sarah Maill, Young ia Co-ordinator - ia (The Ileostomy and Internal Pouch Support Group) Great Britain and Ireland, I shall put to paper the experiences of a group of young ostomates who came together from around the world over the weekend of 28th – 31st August 2004.

The organising committee, Damaris Morais from Brazil, Paula West from New Zealand, Marc Bekkers from the Netherlands, and myself, Anne Hafner from Australia, will have these dates eternally embedded in our memories; because for the past eight months we have only ‘breathed, ate and slept’ 20/40. I would like to express thanks to my committee for the tremendous effort they have each put in to making this Focus a success and for making my task as Chairperson an enjoyable one. In addition, I wish to say a big ‘Thankyou’ to the IOA for hosting and encouraging our participation in this our 3rd 20/40 Focus.

There were 24 delegates this year that represented the following countries: Australia, Belgium, Brazil, Czech Republic, Estonia, France, Germany, Israel, Malaysia, Netherlands, New Zealand, Norway, United Kingdom, and USA. A low figure but still a very enthusiastic and motivated team of young ostomates.

From Sarah...

Over the past five years I have been incredibly lucky to attend all three 20/40 Focus conferences due to generous funding from ia’s Bryan Brooke Travel Fund and would like to take this opportunity to thank ia for their continued support and encouragement. 20/40 Focus is an international conference for young ostomates and young people with continent procedures, between the ages of 20 and 40, to come together to share experiences and exchange ideas. It is a fantastic opportunity to meet people from all over the world and to establish a worldwide network of young, committed and motivated ostomates. The 3rd 20/40 Focus Conference was held in Porto, Portugal between the 28th and 31st of August in conjunction with IOA’s World Congress. This was the first time the two conferences had been held at the same time and we were all very interested to see how this would work.
I traveled to Porto with three other young delegates; Laura Dunn, Jonathan Legge and Rachel Hayward. As we landed at Porto airport we were pleased to see bright blue sky and beautiful sunshine, a vast improvement on the wet British weather we had left behind. Whilst waiting for our suitcases we bumped into some of the other UK delegates and realised that ‘Team GB’ was going to be a strong contingent, as there were ten of us altogether. We had six youth delegates attending 20/40 Focus and four delegates attending the IOA World Congress.

On arrival at the hotel, familiar faces from past conferences greeted us. Once everyone started chatting it felt like we had only seen each other last month instead of three years ago in Hamilton and we introduced ourselves to the ‘first-timers’. It always amazes me how friendly everyone is and we quickly arranged to go out for dinner. We went to a fantastic restaurant on the Riberia, along the River Douro. This was the beginning of the unique bonding experience that surrounds 20/40 Focus. It is difficult to describe the intense friendships that develop between delegates; all I can say is that you need to experience it to believe it. Everyone understands everyone else’s needs and can empathise with what each individual has been through. One delegate told me that when she attends events like this she is a completely different person, as she feels much more relaxed and honest. Whereas at home she feels more guarded and secretive, as not everyone knows she has an ostomy. This is why 20/40 Focus is important as it provides a forum where young people can come together and discuss ostomy related issues. It is particularly important for those delegates from poorer countries where stoma care and appliances are limited, as they need our support.

After the Grand Opening on Saturday we had a getting-to-know-you session, where we played several icebreaker games. The small presence of delegates was disappointing as there were 41 countries represented at the IOA World Congress, which meant that 27 of them did not bring a young delegate. However, in the IOA open forum we challenged these countries to bring a young delegate to the 4th 20/40 Focus in San Juan, Puerto Rico in 2007. Although, delegate numbers were low compared to previous conferences it enabled us to bond as a group and we were all able to get to know each other. Whereas in the past delegate numbers were much higher and you did not have the opportunity to talk to everyone as people tended to form small ‘friendship’ groups.

During our first open discussion it became apparent that the three main reasons why delegates wanted to attend 20/40 Focus were: to meet other young ostomates; to see how other countries support young ostomates; and to discuss youth ideas and initiatives. These demonstrate the importance of 20/40 working in conjunction with IOA to support young ostomates around the world, as the youth of today are IOA’s future. By working in unity with IOA we can learn about leadership roles, be involved with IOA’s infrastructure and foster stronger relationships between us.

With the 20/40 Focus running alongside the IOA World Congress we had the opportunity to attend IOA’s business meeting and a range of workshops. Harikesh Buch, a surgeon from Bombay ran a workshop entitled ‘Adaptation After Ostomy Surgery’ which was excellent. He discussed how people cope differently to life with an ostomy and how important positive mental attitude is when faced with a life changing experience. He also discussed the impact an ostomy can have on body image and how adaptation is essential for life. We were also able to discuss these issues further during the 20/40 Focus workshop on body image and relationships. Unfortunately, due to time constraints this workshop was cut short which was disappointing, as people had just begun to open up and raise important issues that needed to be discussed and explored further.

The visiting workshop involved breaking into small groups to discuss the importance of visiting, whether we’d had a visitor and if our countries associations had a visiting programme. As you can imagine everyone’s experiences were different and it made me realise how lucky we are in the United Kingdom to have a successful visiting service. This workshop also enabled us to learn more about healthcare in each other’s countries and some of the stories I heard were terrible. They actually made me feel quite humble. The next time I criticise the NHS (National Health Service) I will think about ostomates in countries such as Estonia and Brazil who have very limited support and ostomy appliances. In some countries people have to improvise and make their own ostomy appliances as they cannot afford to pay for them or there is a severe shortage of supplies. In the UK we are fortunate that we are exempt from paying for our prescriptions and that we are able to have as many ostomy appliances as we want.

One of 20/40 Focus’s aims is to enable young ostomates to share ideas and exchange information such as how to organise meetings for young people and this was the topic of one of our workshops. We also had the opportunity to give a brief country report...
about how we support young ostomates. These two sessions were informative and gave me lots of ideas as the majority of countries represented at 20/40 organise annual youth camps and this is something I want to develop in the UK. I also attended the IOA workshop about organising youth camps, which was led by Pat Cimmeck of UOAC. She showed us a short video about the Canadian Youth Camp, which encourages children and young people to realise that they are not alone and that there are other young people with ostomies. To be honest I found the video quite moving and it definitely inspired me to try harder to support ostomates under the age of eighteen here in the UK as this is something I feel that Iastruggles to do.

As well as the business meeting, the workshops and discussions there was plenty of time to socialise at both the IOA World Congress and 20/40 Focus. The opening dinner was held at Casino da Povoa, where we were entertained by ‘Feelings’ the Casino’s new show, which took us “from the sensual tango and bohemian 1920’s through to the magic world of geishas to the erotism of strip.” It certainly caused a stir amongst some of the delegates. On Sunday we had a free evening to explore Porto and most of the 20/40 delegates went to the Riberia again for dinner and on returning to our hotel stayed up into the early hours getting to know each other. The next afternoon we had a city tour of Porto, which was interesting and we even had some free time to explore before we went to The House of Sandeman for a tour around the port cellars and a port tasting session. The city tour was completed by dinner at a riverside restaurant where the beer flowed all night. Prior to this the 20/40 delegates were seen as the ‘rowdy’ ones but this time we were overshadowed by some of the IOA delegates who started singing and throwing paper aeroplanes! This proved that no matter what age people are they want to have fun.

For the 20/40 delegates the final day began with a stress relieving session led by Luis Filipe Pinto (Chair of the Organising Committee). This involved going to a local park to play handball and football, which ended up being very competitive and physical. Despite being at an advantage (there were 14 females playing against 8 males) the girls lost but it was a great way to start the day and good fun. Both conferences ended with a closing banquet and dance held at one of the local wine cellars on the River Douro. This was a fantastic way to end the IOA and 20/40 Focus experience as everyone appreciated the Portuguese food and wine and there was a great atmosphere. The band was excellent and was quite happy to play requests and virtually everyone demonstrated their dancing shoes at some point through the evening. Yet again the 20/40 delegates stayed up socialising until the early hours and it was soon time to say goodbye.

I had a fantastic time at 20/40 and met some great people. I have come home with memories that will last forever and have been inspired to take my involvement with IOA and 20/40 further by being on the next 20/40 Focus organising committee. I believe it is vital that we raise the profile of young ostomates and have a voice in how our local, national and international associations are run. We need to learn, share and connect in order to improve the quality of life of young ostomates around the world. I look forward to seeing you in Puerto Rico in 2007!

Well-said Sarah, and Thankyou again.

I would finally like to say ‘Thankyou’ to all the 20/40 participants for their undying enthusiasm and positivity throughout these past four days. This has been a unique opportunity for each and every one. We made the most of these few days and we go home with wonderful memories of shared experiences and lasting friendships. Remember ...

Life’s journey is not to arrive at the grave safely in a well-preserved body,
But rather to skid in sideways, totally worn out, shouting "... Holey shit ...what a ride!"

Anne Hafner Chairperson 20/40 Organising Committee
**FOW CANADA REPORT**  
by Astrid Graham, FOW Canada Shipping Director

Having nearly completed my first year as Shipping Director of FOW, I’m happy to report a great deal has been accomplished. Living in Ottawa provides an advantage as most of the foreign Embassies reside in the City.

Before I ship anything, I have a meeting with the appropriate Embassy. I introduce them to FOW, explain what we are all about and find out what the Embassy can do to help getting our supplies into their country without problems, holdup or additional cost to the Ostomates. As of the today, I have met with three different Embassies and have scheduled a meeting for three more. These meetings were very successful and I received a lot of cooperation.

To say ‘thank you’ and provide an opportunity for the participants get to know each other, I arranged a FOW Christmas Party at my house on Sunday, December 19, 2004. The weather was snowy and therefore not the best for a party. I was happy that there were only two cancellations. In attendance were three FOW Directors, the Ambassador Ernesto Sentí Darias from the Cuban Embassy with his wife, the Economic Counselor, Antonio Castanon from the Cuban Embassy with his wife and the Charge d’Affairs, Xiomara Perez (representing the Ambassador until he/she arrives) from the Panama Embassy. Also in attendance were a number of FOW members, a major supplier representative and other ostomates, supporters and friends. Nguyen Quoc Cuong, Minister Counsellor from the Vietnam Embassy declined because of another engagement. Christmas decorations adorned the house, there were plenty of drinks, food and everybody had a good time.

FOW shipment news for 2004.

1. **Iran: 869 kg.** A shipment left from Montreal in December 2003 and arrived early in 2004 in Tehran, Iran. Dr. Bahar-Mahjoubi acknowledges receiving the shipment. I had the good fortune in August 2004 to meet Dr. Bahar-Mahjoubi in Porto, Portugal. We had a number of conversations and she mentioned again, that the Iranian Ostomate Association desperately needs Ostomy supplies for the poor Ostomates and she very much appreciates receiving supplies from Canada.

2. **Cuba: 994 kg.** The shipment left July 4, 2004 from Toronto by Cubana Airlines and arrived the same day at the Havana Airport. Because of the serious weather condition within Cuba, it took some time for the Ostomy Group to get the shipment, but it was finally accomplished. The acknowledgment we got from Dr. Llorente reads: “Yes, we have received the entire shipment, we are just making the organization to start the distribution of them next week. Thankssssssssssssss one mooooooooore time, We appreciate you enormously. We see you, love. Dr LLORENTE.” I am happy to report that we received a few photos showing Ostomy group members receiving some of the supplies. As you can see on the pictures, the supplies are well received and ostomy boxes are held with smiles. I created a bilingual (English-Spanish) ‘Declaration of Intent’ form, which Dr. Llorente signed and return to me.

3. **Vietnam: 394 kg.** The shipment left Montreal on December 8, 2004, traveling through Vancouver to arrive in Ho Chi Minh City on January 12, 2005. We are now waiting the confirmation from Dr. Tin. In Porto I met a nurse from Vietnam, Miss Nguyet and we spent a lot of time together. She is looking forward to getting our supplies for the needy Ostomates of their chapter.

4. **Panama: 1,021 kg.** The shipment left Toronto in December 2004, via Miami to Panama City. We are now waiting for confirmation from Fernando Ferrer. I met Fernando and his wife in Porto, Portugal last August and I am comfortable that the supplies will be a very great help to many poor Ostomates.

5. **Cuba: 685 kg.** This shipment arrived by Cubana Airlines from Toronto to Havana on Dec 2, 2004. The reply from Cuba roughly translated reads: “We received the contribution of December 2 and quick we begin to distribute among the ostomizados. Thank you so much for all, happy year 2005. Cordial greetings Dr. Llorente”.

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National Congress of the French Ostomy Association  
(Fédération the Stomisés de France, FSF)  
Nice, 23-25 April 2004 Reported by Thierry Schuster

This year, the national Congress of the French Ostomy Association took place in Nice. It was organized by ILCO Côte d’Azur with the participation of the National Cancer Society and the stomacare companies Braun Biotrol, Coloplast, Convatec and Hollister.

The programme was as follows:

**Friday 23rd April 2004**
General Assembly, election of the new administrative committee, assembly of the medical committee, workshops (hotel Campanile), cocktail (town hall)

**Saturday, 24th April 2004**
Medical Congress, Round Table and discussion, exhibition at the Faculté de Médecine St. Jean d’Angely, Gala Dinner at the Royal Casino of Mandelieu - La Napoule

**Sunday 25th April 2004**
Excursion to the Italian Riviera

On Friday, 23rd April 2004, the representatives of the regional associations, which are members of the French Ostomy Association, elect M. Guy GATIGNOL new President and M. Thierry SCHUSTER Representative of the young ostomates. In the evening, an official cocktail is organized at the town hall of Nice in presence of Professor AYRAUD, representing the Senator-Mayor PEYRAT.

On Saturday, 24th April 2004, Ex-President of the FSF, Dr. DEIXONNE, and Professor HEBUTERNE welcome the participants of this year’s national Congress organized by Gisèle CARTIER and her team.

Professor BERARD, surgeon at the Hôtel Dieu Hospital of Lyon presents the lectures: “Crohn’s disease” (Professor HEBUTERNE), “Urinary infections” (Professor AMIEL), “Nutrition for ostomates” (Dr. SCHNEIDER), “Techniques avoiding ostomy surgery” (Professor BENCHIMOL), “Cancer: Chirimotherapy and Radiotherapy” (Professor GERARD), “Stomatherapy – role of ET nurses” (M. VIGNERIE), “The KID CLUB” (Dr. KURZENNE, Dr. STEYAERT)

Mrs. CUNY, mother of a young ostomate (student of medicine who wants to become a surgeon), reads a very encouraging letter from her son who is an ostomate since his childhood.

An interesting Round Table and discussion follow the lectures.

The great importance of a good collaboration between different medical experts, ET nurses, stomacare companies and ostomy associations for a better life of all ostomates is emphasized.

The Gala Dinner sponsored by Braun Biotrol, Convatec, Coloplast and Hollister with its mimes, magicians etc. crowns this year’s national Congress of the French Ostomy Association.

On Sunday, 25th of April 2004, the trip to the Italian Riviera (Eze, Vintimille, Dolceaqua) is a great success.

**IOA PRESIDENT ATTENDING JOA CONFERENCE**

The 17th Japan Ostomy Association (JOA) National Conference of 2005 will be highlighted by the participation of IOA President Dielwen Bracken. It will be held in the southernmost island of Kyushu for four days beginning May 19.

Scenic Miyazaki Prefecture is noted as the birthplace of the nation, according to Japanese mythology. The last two days will be devoted to bus tours of scenic spots.

Over 300 ostomates, headed by JOA President Kozo Inagaki, headquarter executives, 65 chapter officials and participants from Hokkaido in the north to the southern island of Okinawa will attend.

On the first day of the conference, JOA headquarter executives and chapter officials will exchange information and discuss management policy, including the new JOA budget, as well as pending issues and future goals.

At the General Conference on the second day, the guests will be IOA President Bracken, the governor of Miyazaki Prefecture and welfare officials assisting ostomates. Ms Bracken will be the first IOA President who attends JOA National Conference. IOA President is scheduled to speak on “The Ostomy World Is United As One Family”. The subtitle of her speech is “The Activities of Future International Cooperation.”

One of the problems still facing JOA is the cancellation of the Nara IOA World Congress in 1997. Since JOA members were making every effort to make the Nara conferences succeed. There have been, among some JOA chapter members, a remarkable decline of interest
to keep relationship with overseas ostomy groups and even insisted on to withdraw from IOA. JOA hopes that the visit of President Bracken will help provide and opportunity to remedy the situation.

**Two key topics will be discussed at the National Conference.**

**The first topic** is the problem of changing and fitting new pouches for aged bedridden ostomates at home. Many of them live alone. In Japan there is a system known as "Health Care Insurance ". Under this system qualified helpers are sent to the homes of aged patients requiring assistance. But the so-called home helpers are not allowed to change pouches of ostomates as it is considered an illegal "medical act." But home helpers are allowed to change diapers. JOA is making strong efforts to change this situation by seeking the help of Nursing and Disability Assistance Associations.

**The second topic** is to increase the number of toilet for ostomates. JOA has made major progress in this sector. JOA succeeded in persuading the Japanese Government to build toilet for ostomates at public facilities. There are about 1,800 such toilets at present, but not enough. The toilets are located at major Japan Railways (JR) stations, public facilities and department stores. Most adjoin toilets for the handicapped.

The toilet movement began six years ago when a female Ostomates used a toilet for the handicapped at a public facility to change her pouch. When she opened the door, a waiting wheelchair person strongly scolded her for using the disability toilet. She launched a campaign which resulted in the building of the first toilet for Ostomates at the city office in her hometown.

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**A busy year ahead**

We have just entered a very busy year for NORILCO, Norway. Our very tight connection to the Cancer Union in Norway will continue, and our premises will still be under the same roof as the Cancer Union. One major change may still occur. NORILCO will probably from mid-summer be the employee with all the duties and responsibilities for our three employees. Up to now those duties have been taken care of by the Cancer Union. A great change which will be taken to an extraordinary general assembly in April. Hopefully this take-over will be to the best of all parties, and as president of NORILCO I am most happy that as well the different local chapters, the EC and the employees have a positive attitude the change.

We are lucky to be able to launch four new projects with money from Health and Rehabilitation this year. Two of them will our young association be responsible for. One of these will be a visiting course for young people – very important, for just think of the unsecurity a young ostomate (or IAA) will have compared to an older one. The other is about “it’s hard to live together with a person with a permanent illness”. The young group will have their annual winter and summer camps as well.

For us more grown Rigmor Yttergård will arrange a gathering especially for people with urostmi, and Jostein Sandvik’s gathering will be for parents, brothers and sisters of an Ostomy child. This time we will focus most on the brothers and sisters, says Jostein Sandvik.

NORILCO has the honour of hosting the Nordic meeting this year. The meeting will take place in the soft part of Norway, on the south coast in august. With a little bit of luck the sea will still allow the participants from Iceland, Finland, Sweden, Denmark and Norway to take a swim in the refreshing sea-water.

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**United Ostomy Association of Canada Inc. (UOAC)**

Hello Everyone. We here in Canada are ready for spring. All across the country, we have been deluged with snow and everyone is getting very tired of it. With thoughts turning to spring, we think of the new projects underway and the annual events that we all like to take part in.

Plans are well underway for our annual conference. This year it will be held in Winnipeg, Manitoba August 18-20, 2005. This is always a highlight of our year. The many volunteers, who organize the conference, work very hard to ensure all participants enjoy an educational and entertaining experience. This year will be no exception. So come join us and “Feel Alive in 2005” August 18 – 20.

For those who enjoy the game of golf, we will again hold our annual Golf Tournament, July 14, 2005. This event is a day filled with fun, prizes and fellowship. It also helps to publicize UOAC and what we do.
Thank you to all of you who have sent congratulations and greetings to the editor of our magazine, Ostomy Canada. We are very proud of our publication and appreciate your requests to reprint articles from our magazine in your own publications.

We in Canada wish you continued success with the endeavors of your associations.

Pat Cimmeck, President
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http://www.ostomyinternational.org/officers.htm

http://www.ostomycanada.ca/uoac_annual_conference.htm

The Forum includes many features:

- Able to edit message before posting
- Notification when your posting has had a reply
- Send email to the user
- Send private message to the user
- View user profile
- Add user to your buddy list
- Page on AOL Instant Messenger
- Page on ICQ
- Profile
- Bookmark
- Personal inbox
- Signature
- Ability to hide profiles, inbox, ICQ, and email
- Search Forums with keyword or words
- Reading new or recent topics search

There are many more features than the ones listed above.
Read FAQ found on the main Forum page and learn how to use these features.

Please note: you do not have to register to use this new Forum.
However if you choose not to, then you will not be able to use many of the features.