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The IOA Regions reporting, through their presidents, in this issue of IOA TODAY are the the EUROPEAN OSTOMY ASSOCIATION (EOA); ASIAN OSTOMY ASSOCIATION (IOA); South American Ostomy Association (ALADO); NORTH AND CENTRAL AMERICA AND CARIBBEAN OSTOMY ASSOCIATION (NCACOA).

(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

Dear Friends

I would like to take this opportunity to remind you why the Executive Committee had to take the unpleasant decision of canceling The World General Assembly which was to take place in Bangkok in 2003.

Due to the outbreak of SARS disease in Asia at the beginning of this year and the warnings we were getting from the World Health Organization we decided that the risk that anything could happen to our members was too great. This was a very unpleasant decision, however after consulting our legal adviser it was considered fully justified .

We are now happy to announce that the World General Assembly will take place together with the European Regional Meeting in Porto, Portugal. The set dates for the two meetings are from the 4th October to the 9th October, 2004.

The first two days will be devoted to the EOA Congress to be followed immediately by the IOA Congress from the 6th to the 9th inclusive.

We have taken every consideration possible to make this a successful combined meeting, at the most economical registration fee, so as to give the opportunity to have as many attendees as possible. We would like to see as many as possible from your various organizations, to be with us and to share this event with us .

Registration fees are as follows :

EOA only EU 100 .-

IOA only EU 200.-

IOA + EOA EU 250.-

Hotel information will be sent to you as soon as final agreements have been signed with the Organizing Committee .

We hope to see as many as possible in Porto by next year

With best regards

Heinz Wolf President IOA



Signing of contract



From the IOA Vice President

Di Bracken
ioavicepresident@ostomyinternational.org

The World Heritage City of Porto is home to the 11th IOA Congress.

IOA in cooperation with the European Ostomy Association and the Liga de Ostromizados de Portugal (LOP) invite you to join them for the 11th IOA World Congress to be held in Porto, Portugal in October 2004.

This will be a most interesting experience for World Congress attendees as you will be able to participate in two Congresses if you so desire in an absolutely intriguing location.

Portugal's second-largest city, Porto retains all the charm of a riverside community while still keeping alive ancient traditions. The town is named on UNESCO's World Heritage List, while still being being the country's most important commercial and manufacturing area.

Porto is built on steep granite hills overlooking the River Douro, with a mass of 19th-century narrow streets and alleys at its heart. The river is straddled by five bridges that connect the town with the Vila Nova de Gaia area, traditional home of the port-wine lodges and Porto's largest tourist attraction. Theatres, live music of all kinds, bars, nightclubs, cafés and restaurants provide interesting activities for all tastes. I fell in love with the attractive red roofs throughout this hilly city – something that we do not see in Canada.

At the Riverside area of Ribeira you can find a combination of old-fashioned fishing district, elegant restaurants and smoky bars. Stroll by the River Douro and visit the bustling downtown area. Explore the narrow lanes and cobbled

alleys. Porto has many interesting churches but must-sees include the 12th-century cathedral, the Clerigos tower and church, the astonishingly ornate church of Sao Francisco and the church of Carmo with its stunning tiled facades. As in all European cities there are several excellent museums to visit.



(Continued on page 2)



Take a river cruise and experience the town's five bridges from a river perspective, boarding in the Ribeira or near the Ponte de Dom Luis I at Vila Nova de Gaia. Join in the hustle and bustle of the Mercado do Bolhao, a lively street market in the town centre.

It would be a great idea to arrive early and stay on after the Congress as there is so much to see and do. There will be an opportunity to take a tour if you are so inclined. We will be providing more information on the availability of tours and various destinations, once we have completed negotiations with the venue for the World Congress. LOP IOA is currently conducting negotiations with three hotels and our president Heinz Wolff will return to Porto in September of this year to give IOA's approval to the final selection.

The European Congress will open officially on Monday 4th October 2004 when the business meeting of the EOA takes place. This continues through Tuesday 5th October when those taking in the IOA World Congress only will arrive.

Wednesday, 6th October 2004 at 9:00 AM will be the Grand Opening of the IOA Congress with its traditional "Parade of Flags" – always a very moving experience. The World Congress will continue through **Saturday 9th October 2004** when the Closing Banquet will be held. We have allowed some free time so that all attendees have an opportunity to explore this historic city of Porto.

I know that you will all be interested in the costs for the Congresses. The following registration fees have been established:

- EUR 100 for the EOA Congress only
- EUR 200 for the IOA Congress only
- EUR 250 for EOA/IOA

Our next edition of IOA TODAY will be sent out on October 31st 2003 when we will have further details regarding hotels, tours, programme and other tidbits of information. As I receive further information, I will pass it along to our Webmaster who will get it onto the Website , so keep watching the website

This was my first visit to the country of Portugal, and as fleeting as the visit was, I was truly enchanted by Porto and am looking forward to spending some extra time there next year following the Congress. Luis Filipe Pinto, President LOP and Dr. João José Vieira Amândio, President of the General Assembly of LOP will be looking after the Congresses. Originally, these two gentlemen had agreed to host the European meeting; now they find themselves facing the challenge of hosting the IOA World Congress in addition and with very little time to do so. However, they are excited by the prospect of showing off their World Heritage city to the rest of the Ostomy World. They were most gracious hosts for this business meeting and I know that you will enjoy the warm, caring friendliness of the Portuguese people when you join us for the Congresses.



Di Bracken, Vladimir Kleinwächter, Heinz Wolff, Luis Filipe Pinto and Dr. João José Vieira Amândio

Please take good care of yourselves and stay safe and in good health.

Di, ioavicepresident@ostomyinternational.org

Discussion Forum

<http://www.ostomyinternational.org/cgi-bin/dcforum/dcboard.cgi>

**The Conference
Devoted to the 10th
Anniversary of Moscow City
Stoma Patients Rehabilitation
Service and
Regional Public Organization
of Stoma Patients "ASTOM"**

**Cultural Center "Moskwitch",
Moscow, Russia
April 2, 2003**



Alexander Gordeev



President
Sukhanov

- ASTOM Association achievements in the development of invalids rehabilitation process in Moscow and assistance rendered by ASTOM to regional organizations of stoma patients;
- importance of the actions devoted to World Ostomy Day and development of the relations with International Ostomy Association, exchange of experience with international ostomy organizations;
- cooperation with mass media;
- importance and actuality of the development of stoma patients medical and social rehabilitation scientific foundation; for this purpose ASTOM organization closely cooperates with two chairs of Moscow University of Services – chair of medical and psychological rehabilitation and chair of sociology and public activities.

In the conclusion the speaker pointed out that the basis of the success in the course of stoma patients rehabilitation lies in integration and coordination of the efforts of all participated in the rehabilitation process – state health and social care institutions, commercial structures that manufacture stoma care products and public stoma patients organizations.

The conference was closed with a concert. Some prominent singers and dancers took part in the concert:

- children song theater "Shliager" (Smash hit) under the leadership of Natalie Gorban;
- popular Russian singer Anatoly Kuibyshev;
- Honored artist of Russia Tatiana Filimonova with her group.

There was a cocktail party for invited guests where people had the opportunity to talk in a warm unofficial atmosphere.

Alexander Gordeev, Vice-President



474 members of ASTOM association as well as Moscow Government representatives, officials from Moscow Department of Social Welfare, Moscow Health Care Department, Moscow Committee of Public Relations, people from Moscow and regional hospitals and medical institutions, teachers and students from Moscow University of Service, employees from social welfare services, representatives of stoma care products manufacturers, representatives of regional stoma patients associations (ASSCOL, St. Petersburg; KASTOM, Krasnodar; URALSTOM, Perm; BELAS, Belarus) and mass media took part in the Conference.

There was an exhibition organized in the main hall of the Center. The following companies took part in the exhibition:

- ostomy appliances manufacturers – ConvaTec (Great Britain), Coloplast (Denmark) and Russian company "Palma";
- medical and production company "Zdorovie" manufacturing bandages;
- sub-faculty of medical and psychological rehabilitation of Moscow State University of Service;
- the Center for invalids judicial and social assistance;
- "Sunrise" company producing medical herbs;
- "ASTOM".

The first deputy Major of Moscow Mrs. Shvetsova, the Chairman of Moscow Government Public Relations Committee Mrs. Vasilieva and the President of the European Ostomy Association, Vladimir Kleinwachter sent complimentary addresses to the conference.

"ASTOM" President Mr. Sukhanov made a speech that covered the following problems:

- increase of invalids number in Russia;
- problems of stoma patients in Russia;
- role of public organizations in psychological rehabilitation of stoma patients;

The Chronology of the main events in the activity of the Moscow Organization of Ostomy Patients “ASTOM”

March 23, 1993 – Association of Stoma Patients “ASTOM” was officially registered by Moscow Department of Justice.

April 24, 1995 – Moscow Health Care Department allotted salaries for doctor, nurse and orderly to organize a stoma patients service room in the 24th City Hospital.

June 27, 1995 – Moscow Health Care Department and Bristol-Myers Squibb – ConvaTec (Great Britain) signed the first contract to supply stoma care products to Moscow.

January, 1996 – stoma patients service room in the 24th City Hospital started to provide stoma patients with stoma care products.

September, 1996 – participation in the working out of Moscow Health Care Committee order concerning the supply of stoma patients with ConvaTec stoma care products.

December, 1996 – Stoma Patients Psychological Rehabilitation Service was created with the support of Moscow Government Committee for Social and Interregional Relations.

April, 1997 – ASTOM representatives participated in the International conference of stoma patients associations in the town of Brno (Czech) for the first time.

January, 1998 – a new name of ASTOM organization - Regional Social Organization of Invalid Stoma Patients “ASTOM” - was approved and reregistered.

February, 1998 – together with Moscow Committee for Public Assistance ASTOM took part in the development of “The Moscow Complex Task Program for Invalid People Rehabilitation”. As a result of this work Moscow Government accepted the Program that included the issue “Creation of the stoma patients comprehensive rehabilitation model”. ASTOM was made responsible for this issue.

May, 1998 – Moscow City Charitable Council approved “The Creation of the Stoma Patient Rehabilitation Center Program” that got the status of a city program.

November, 1998 – “ASTOM” was rewarded with “The Diploma for the development and strengthening of the charity activities in Moscow”.

December, 1998 – participation in the development of Moscow Health Care Committee order “Concerning stoma patients provision with “ConvaTec” stoma care products and creation of a new system of stoma patients supply with these products” (Order #64, February 11, 1999).

November, 1999 – the Board of Moscow Health Care Committee made a decision to approve the joint activities of “ASTOM” and the 24th City Hospital aimed at stoma patients rehabilitation.

March, 2000 – “ASTOM” president made a report at the meeting of Moscow Government devoted to health care problems and tasks.

April, 2000 – “ASTOM” was affiliated to the International Stoma Patients Association as an associate member.

April, 2000 – for the first time “ASTOM” was acknowledged internationally at the World Congress of Stoma Patients Associations in Amsterdam and rewarded with a special prize for the achievements made in the sphere of stoma patient rehabilitation.

September, 2000, October, 2001 and November, 2002 – participation in the International expedition “The Planet and Health”.

January, 2001 – participation in the development of “The Complex Task Program for invalids rehabilitation in 2001-2003 years” approved by Moscow Government.

December, 2001 – publication of the first and the only issue of the brochure “Stoma Patients Rehabilitation. The Problems and Solutions”. The brochure was designed specially for stoma patients and their relatives.

July, 2002 – “ASTOM” program “Social and common rehabilitation of invalids with stoma” became a winner in the Contest of socially important programs worked out by public and noncommercial organizations announced by Moscow Government Committee for Social and Interregional Relations.

November 2003 – the Conference devoted to the 10th anniversary of the City stoma patients rehabilitation service and “ASTOM”

Russian regional public organizations of stoma patients:

“ASTOM” – Moscow

“ASSKOL” – Saint-Petersburg

“KUBSTOM” – Krasnodar

“URALSTOM” – Perm

“KRASTOM” – Krasnoyarsk

“ROOSI” – Rostov-on-Don

“BURASTOM” – Ulan-Ude

“ASTOMA” – Orenburg

There are public organizations of stoma patients in Ukraine, Latvia, Lithuania, Estonia and Byelorussia.

The total number of stoma patients in Russia is about 120 000 people.

The number of stoma patients in some regions of Russia:

Moscow – about 7000; Moscow region – about 3000; Saint-Petersburg – about 5000;

Perm and Perm region – about 2500; Krasnodar and Krasnodar region – about 3500;

Krasnoyarsk – about 3000.

Statistics of the budget for purchasing stoma care products for one person a year:

Russia: Moscow - \$250; Saint-Petersburg -\$200; Krasnodar, Perm and Krasnoyarsk - \$90; other region have no budgets for these purposes.

The main directions of “ASTOM” activities:

- development and realization of charitable medical, social and other complex task programs and actions aimed at medical and social support of stoma patients;
- assistance in supply of stoma patients with modern stoma care products;
- support of the Russian stoma care products manufacturers in their development;
- support of the development of new methods in proctology and propaganda of these methods (stoma therapy etc.), together with doctors assist patients in the rehabilitation after the operation, support of stoma rooms organization;
- organization of social and psychological rehabilitation services for stoma patients to help them to overcome depression and to render them moral assistance after the operation or to help them to prepare for the future operation;
- social support for poor patients;
- organization of employment service for those looking for job;
- assistance in marriage and creation of a family;
- organization of home visiting service for disabled patients.

Every year about 600 stoma patients and their relatives receive psychological assistance.

Every year about 200 people with stoma visit theaters, concert halls, exhibitions and museums free of charge.

Monthly we deliver a lecture "Life with a stoma".

Constantly we render information support regarding medical and social, common and labor rehabilitation of stoma patients as well as give our people legal assistance.

In the frame of the City Charitable Program worked out by "ASTOM" in 1998-2001 we managed to do the following:

Actions and services rendered	Number of people	Amount in RUB
1. goods	Free supply:1.1	Sanitary and hygienic goods1.2
1.3 Foodstuffs	Biologically active additives1.4	Personal hygienic Manufactured goods1.5
2. Free tickets to sanatoriums	83689884267776880	298 44231 018796 160274 67095 184
3. Cultural and social activities	69	160 945
	728	91 778

The 24th City Hospital Stoma Patients Rehabilitation Service was created by the initiative of Moscow chief proctologist professor Alexandrov V. B., M.D., and with "ASTOM" close participation. Cooperation of these two structures created good conditions for complete rehabilitation of stoma patients. One of the directions of the Service's activity is to render assistance to invalid people at home.

"ASTOM" actively cooperates with mass media.

We published 16 articles in newspapers and magazines, including international magazines. The brochure about ASTOM activities were issued three times in Russian and English. For the first time we published special manual for stoma patients "Stoma Patients Rehabilitation. The Problems and Solutions."



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

EOA ADVOCACY WORKSHOP

1st May 2003



Gyula Horvath (Hungary), Dr. Özgür Oner (lecturer, Germany), Robert Bailey (Great Britain), Prof. Dr. Nicola Vito Grimaldi (Italy), Ria Smeijers (EOA/Netherlands), Dr. Vladimír Kleinwächter (EOA/Czech Republic), Heinz Wolff (IOA/Israel), Ingrid Schumacher (Germany), Maxim Kostjuchenko (Ukraine), Helga Englert (Germany), Lilija Kuznetzowa (Ukraine), Wilfried Eynatten (Belgium), Prof. Dr. Carlo Pezcoller (Italy), Arne Holte (Norway), Anna Gromadka-Keska (Poland), Giuseppe Gatti (Italy), Maria Haß (Germany), Prof. Dr. Gerhard Englert (Germany)

1st – 4th May 2003, FRANKFURT

Report prepared by Dr. Vladimír Kleinwächter, President
EOA

Photographs courtesy Professor Gerhard Englert, President,
Deutsche ILCO

The Advocacy Workshop was organised by Deutsche ILCO on the basis of the decision of the 10th EOA Congress. The venue was Haus der Parität in Frankfurt am Main, which offered an ideal setting for the meeting.

The invitation received all European member Associations together with a questionnaire, which covered the principal areas of the health care of ostomates - the system of stoma care reimbursement, deficits in stoma care and activities of ostomate organisations. It is only a pity that the questionnaire was returned only by about one third of member Associations (13 out of 38). The attendance at the Workshop was even smaller, participants from only 11 organisations (see Appendix 2) arrived. Nevertheless, the participants represented the main European regions as to the care of ostomates, i.e. western, central and eastern Europe. The questionnaires were summarised by Professor Englert in tables, which were distributed to the participants as starting Documentation for the Discussion.

The Workshop was opened by Professor Gerhard Englert, Chairman of Deutsche ILCO, and the participants were greeted by Dr. Vladimír Kleinwächter, EOA President, and Heinz Wolff, IOA President, who was present as a guest.

The participants then introduced themselves and gave a brief characterisation of the Associations.

In the introductory part Professor Englert explained the basic aims of the Workshop. In 2004 the community of the European Union will be enlarged to contain 25 members. In the future it will be necessary to co-ordinate the care of ostomates in the member countries. The first step is to define the needs of ostomates. Then we must recognise the situation in the individual countries, find out the deficits and start with advocacy activities on national level and, if possible, on the level of EU. It is not envisaged that the social and health care policy in the countries of EU will be unified, but is our interest that the level of the care of ostomates will not substantially differ in the European countries.

Professor Englert gave an overview of the information collected from the questionnaires. The basic prerequisite of the life with stoma is an adequate supply of stoma appliances, which are fully reimbursed. In most countries of western Europe the supply is unlimited, in central Europe more or less suitable limits (either in numbers of financial) are applied. However, in some countries of eastern Europe, e.g. in Ukraine or in the major part of Russia, free appliances are not available at all. In all countries there exist apprehensions of worsening the situation, i.e. introduction of partial payment connected possibly with a decrease in the limits. Good care of ostomates requires good co-operation of physicians, stoma therapists and the patients. This is also not always ideal in many countries. In particular, in some cases the patients do not receive full information about the appliances available and often have no choice to use the most appropriate type of appliance.

It followed from the discussion that it is essential to ensure that the Charter of Ostomates' Rights is observed in all countries. In order to suit better the present situation in Europe (and most probably in the whole world), it was decided to slightly modify the existing Charter. The main changes concerned the preamble and the last item, in which the protection against any form of discrimination was mentioned. It was also generally agreed that ostomates should be classified as disabled persons. Otherwise in countries with a low level of the care of ostomates the state institutions would not feel obliged to provide any assistance to this group of people.

It was decided to submit the modified Chart to the IOA Executive Committee and use it as a scheme for preparing reports of national Associations.

2nd May 2003

In the morning session Dr. Özgür Öner, representative of German Welfare Association at the EU gave a presentation on Guidelines for Advocacy Management in EU.

He outlined the structure of Management of EU and defined the advocacy activities as lobbying on European level. The lobbying requires to specify the problem and the objective and then to prepare the strategy.

General strategy in lobbying should include:

- (1) collecting of information (so-called early warning);
- (2) analysis of political, economical, financial, technical and social factors involved;
- (3) exploitation of accessible sources (e.g., databases);
- (4) collecting information from own national decision-makers.

In case of ostomate activities it is impossible to outline a general strategy. It is necessary to identify the decision-making process using own decision-makers and then to prepare strategy first on national level and then on the European one. It may help co-ordinate the action with other organisations having similar goals. Also a network of personal contacts must be built up in major member countries and EU headquarters, mainly with the decision makers.

In the afternoon session possibilities of EOA to carry out an advocacy programme in the EU were discussed. It is clear that the standard lobbying is out of question for financial reasons. It was decided that EOA shall ask for expert registration in an advisory committee of the European Economic and Social Committee. Professor Englert offered to do it with the help of Dr. Öner. Inside EOA there was formed a working group for contact with EU agencies. Its members are Maria Hass from Germany, Ria Smeijers from The Netherlands, Wilfried Eynatten from Belgium and Arne Holte from Norway. The first task of this group is to identify in EU institutions the persons, who might be important for us.

Generally the lobbying is quite expensive process. However, in some cases similar activities of industry or of welfare organisations may be exploited.

Professor Englert closed the Workshop by thanking all participants for their contributions and invited all for a walk through the historical centre of Frankfurt, which ended by a dinner in the restaurant “Steinernes Haus”, sponsored by Deutsche ILCO.

The Workshop helped us to unify the view on several matter, which might become important in forming the European policy towards disabled people. It gave us also an information on how different agencies of the EU work and how we eventually could affect the decision making processes.



Workshop discussions



Evening small talk

I would like to thank the organisers from Deutsche ILCO, Helga and Gerhard Englert and Maria Hass and, last but no least, Dr. Özgür Öner for his instructive presentation.

Belgium / Stoma Club Antwerpen

Wilfried Eynatten; Martine Ghijs

Czech Republic / EOA

Dr. Vladimír Kleinwächter

Germany

Professor Gerhard Englert; Helga Englert; Maria Haß; Ingrid Schumacher

Germany / EOA

Klaus Schröter*

Great Britain

Bob Bailey

Great Britain / EOA

Thomas Keily*

Hungary

Gyula Horváth; István Hegedüs; Professor László Ritter

Italy / A.I.STOM

Francesco Diomede*; Professor Nicola Vito Grimaldi

Italy / F.A.I.S.

Giuseppe Gatti; Professor Carlo Pezcoller

The Netherlands / EOA

Ria Smeijers

Norway

Arne Holte

Poland

Anna Gromadka-Keska

Ukraine

Maxim Kostjuchenko; Lilia Kuznetsova

Guest

Capt. Heinz Wolff, IOA President

* apologised for illness

NEWS FROM NORILCO reported by ARNE HOLT

So far year 2003 has been a busy year for officers and employees in NORILCO. Our office in Oslo is located together with – and in tight connection with – The Cancer Union. In fact all the seven organizations affiliated to the Cancer Union are in the same building. In February next year they all move to another place closer to the center of Oslo giving better access for the public – and other advantages.

Our shipments to ASSCOL in St.Petersburg takes place as before. As the city celebrates 300 years anniversary this year the grants from the city government will be less than usual so our shipments so far has been rather great. A chain of pharmacies in Norway gave us a lot of surplus appliances in February. The Danish company Dansac and Copa, Denmark offered help and about 40000 units bags and wafers were sent to ASSCOL from Dansac. This fall we will arrange a trip for our member to St.Petersburg. In addition to learn to know this beautiful city the participants will meet members of ASSCOL for a lunch or dinner.

In April we had our meeting for local presidents and VP's in Trondheim with about 60 persons present. Among those were the board of NORILCOs Ungdom (the youth group) who are very active in many fields. During the meeting there were reports and also discussion about our activityplan for the next three years. So far several points on the plan has been successfully achieved, but a lot is still to be done.

These days our annual member-camp takes place up in the mountains. 60 members – some of them with their families - gather for a week having lectures, trips, games and so on. In October one of the greatest events ever takes place near Oslo. Then gather nearly 200 visitors for two days for interesting lectures and speeches – and of course also to learn to know each other and hopefully become more keen and better visitors.

For my part I have been busy working on a project paid by the Norwegian Cancer Union trying to high-light if "NORILCOs visiting service shall be a formalized part of the rehabilitation of ostomates". I have had a lot of interviews with hospitals, nurses, parts of the cancer union, local chapters of NORILCO and others. It's obvious that not everyone applaud the idea about "users" shall have a stronger position in the health care. For my part there is no doubt that it is only us – which have a bag or IAA – who know best how this life really is! I am happy to tell that this point of view seems to be shared by the Norwegian Minister of Health who gave me half an hour in his office to tell him about the project.

It is my hope that two or more Norwegian colleges will follow up my work with a greater project among students in rehabilitation classes.

Arne Holte, President NORILCO

NORILCO YOUTH

Being visible in the media has been a major goal for the Youth Group this year. We know that we need to reach the young that are soon to have or just recently had surgery. Too few of these people choose to contact our organisation and become members. NORILCOs YOUTH believe that we have something to contribute and tell to all the young people that have gone through an operation. Luckily we have been able to introduce ourselves in the media on several occasions this year. Our vice-chairman, Brita Gundersen, has taken upon her self to tell about her story and how she has experienced the meeting with government, organisations and how friends have reacted. It's been a personal story she's been telling, making it a brave contribution for the work that we do.

The Youth Annual Meeting (held every second year ☺) has given the Board specific tasks to work on. We are to become more visible to the public, set focus on the problems Youth members face meeting the public services and make the internal organisation stronger. On the next Annual Meeting in 2004 we will introduce a document presenting most of the privileges young people with ostomy and internal pouch have in our country. This document will range from privileges concerning education and economy to tax reduction and economic support if you have to quit your job. We will also present a guide to local Boards which tells how to start and run a local organisation. This is a long desired tool to make our organisation stronger.



Chairman

It's been a busy year for NORILCO's YOUTH and there's more to come. In the autumn we arrange a camp together with our mother organisation NORILCO and a co-operating organisation. This camp will set focus on the people with internal pouches and the special challenges they meet.

Our members are eager to make an effort and to support the work we do. This makes the work easier to overcome and we look forward to present our results on the Annual Meeting in 2004.

Bjørnar Dagstad

Report on the Romanian Surgeons Society, colorectal and stomatherapy conference, Sinaia 16 – 18 May 2003

This major conference, the first of its kind was arranged by the Romanian Surgeons Society (RSS) in conjunction with the Romanian Ostomy Patients Support Foundation U.K. with the Romanian conference organiser Mediacom undertaking all the principal administration in Romania. The U.K. administration was undertaken exclusively by ROPSF.

The conference concept was devised by ROPSF and Professor Dragomir, the current president of the RSS with the aim of bringing together patients, nurses and surgeons with a particular interest in colorectal surgery and with the ultimate aim of increasing knowledge in the area of colorectal surgery and nursing as well as to encourage patients to work more closely with the medical professionals. Education and the opportunity to generate greater awareness in helping patients to achieve a better lifestyle and with medical help, establish or strengthen local patient support groups with the ultimate aim of forming a National organisation.



(National organisation. Brenda Flanagan, Dragos, Petronela, Ciprian, Bob Bailey, Lucia Ciobanu)

The conference attracted a very good spread of delegates from across Romania totalling 869 of whom 49 were patients, 100 nurses with the largest majority being surgeons and doctors. The principal presentations were given by specialist UK surgeons, nurses together with three experienced patient advisors. Three of the main surgical manufacturers, ConvaTec, Coloplast and Ortoprofil were present together with several pharmaceutical and surgical companies all of whom participated in the exhibition and with varying degrees of sponsorship. Further sponsorship was provided by the British Embassy in Bucharest. Other funding specifically in support of the Romanian nurses and patients was raised in the UK through numerous donations.

Due acknowledgement was given to the sponsors, including the British Embassy and a message from the British Ambassador was read out during the opening ceremony on the Friday evening. The conference divided into three separate groups: for surgeons, nurses and patients.

In all cases the lead presentation was given by a UK surgeon, physician or radiologist each relating specifically to colorectal cancer or other inflammatory bowel diseases usually leading to surgical intervention. All of the UK team were experts in their respective fields some of whom had a worldwide reputation

Surgeons' Sessions

The surgeons' sessions were oversubscribed with many more surgeons attending the event than had originally been anticipated. As it was there were parallel sessions throughout the two days making it difficult to choose what to attend!

The main presentations were undertaken in English with questions from the Romanian audience being taken often through translators. Language was a problem on occasions but with so many English speaking Romanians this was often overcome by a brief side conversation. To help matters many of the presentations were graphically illustrated easing understanding of the specialist techniques.



Group of Patients, nurses and doctors outside the conference centre

Following each UK presentation several Romanians made supplementary presentations on similar subjects with further useful discussion.

There can be no doubt that the UK presentations were very well received and many of the surgeons both from Romania and the UK expressed their gratitude in having the opportunity to participate in such a prestigious event. Several UK surgeons have stated that they may well link in with their fellow Romanian surgeons in undertaking further collaborative surgical and medical exercises.

Nurses' Sessions

This was an important element of the conference involving a range of nurses with varying levels of ostomy surgery and aftercare knowledge. The nurses were drawn from hospitals across Romania and had the opportunity of hearing an array of presentations given by four leading UK nurses and other senior nurses from Romania, some of whom had been trained in the UK. The key sessions focussed on an overview of surgical procedures for stoma formation, siting of stomas, together with further practical applications including pain control, nutritional advice, and the outcomes of radiotherapy and chemotherapy in the treatment of colorectal cancer. Other sessions included ostomy appliances, the current state of stoma care in Romania and discharge planning for patients.

To give balance to the conference an expert panel debated with the audience four important areas of patient concern namely, complications of stoma surgery, patient lifestyle including sexuality and body image, as well as social rehabilitation. One of the major spin-offs from this session was the truly remarkable level of sharing of information and the development of networking. Of all the subjects, the siting of stomas generated the most discussion.



Sue Greenfield, Lucia Ciobanu, Theatre Sister Iasi

The practice of stoma siting is in its infancy in Romania and many instances of poorly sited stomas were mentioned. The presentation highlighted the benefit of this procedure to patients which can eradicate some of the extreme distress which may be suffered needlessly due to leaking appliances and of the consequential sore skin in a country where stoma and skin care products are in very short supply.

The final session of the nurse conference was devoted to a presentation about the UK experience of being a member of the World Council of Enterostomal Therapists (WCET), a world organisation



NEWS FROM JAPAN

The 15th Japan Ostomy Association (JOA) Conference was successfully held in Yokohama on June 8 and 9 with about 500 delegates attending.

The ostomates came from Hokkaido in the north to the southern island of Okinawa. Next year's national conference will be held in the southern Kyushu city of Kagoshima.

Yokohama was chosen as the site of the 2003 meeting because the port city is the birthplace of JOA. It was here that a small group of an ostomate doctor and about 10 ostomates organized the "goryokai" (mutual help) organization 35 years ago. As the need to improve the Quality of Life of ostomates grew in this country through mutual cooperation, the "goryokai" changed its name to the Japan Ostomy Association. Today, JOA has 66 chapters with a membership of 12,000. JOA President Kozo Inagaki was re-elected for another two-year term.

One of the most important goals of JOA is to assist aging members as the number of bedridden ostomates is increasing. Under the government's health care program for the aged, only nurses are allowed to change pouches of ostomates. JOA is seeking permission to allow health care helpers who visit bedridden ostomates at home to change pouches and to reduce health care costs..

JOA made progress during the past year to increase public toilets for ostomates throughout the country. The number of public toilets for ostomates increased from 400 to 800. The toilets have facilities to wash and change pouches. They are usually located with toilets for the handicapped using wheelchairs.



JOA was disappointed to learn that the Bangkok IOA Congress was cancelled due to SARS. Since the Bangkok conference was the first ever schedules for Asia, many JOA members had planned to attend the meeting. JOA hopes that the next IOA conference will be held in Asia.

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

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UOA Report by Ron Titlebaum, UOA President



San Francisco Area Chapters.

The leadership team of UOA has embarked on a program it call "Meet the Chapters." This give both local and national leaders an opportunity to talk directly about issues that are important. On May 4 President Ron Titlebaum and Executive Director Nancy Italia met in Oakland, CA with the Golden Gate, Sacramento, Santa Clara Valley, South Alameda, Sonoma County, Solano County, and Placerville chapters. On May 14 they met with the Milwaukee, WI chapter. On June 7 they visited with the Burlington County, NJ; Philadelphia; Audubon, NJ; Abington, PA; Lower Bucks County, PA; Middlesex County, NJ and Wilmington, DE chapters. And on June 8 in New York City they met with the Colostomy Society of NY; Long Island Ileostomy; Brooklyn; Danbury, CT; Morris County, NJ; and Staten Island chapters.



New York City – North New Jersey Chapters



South New Jersey – Eastern Pennsylvania Chapters

UOA networks are moving into high gear. The Parents Scholarship Committee selected eight worthy families to receive sponsorship to attend the UOA Annual Conference in Las Vegas in August. In addition several other families that will be supported directly by UOA chapters. A special Parents Network track at the conference promises to be both strong and well attended. Jude and Cheryl Ebbinghaus, co-chairs of the UOA Teen Network have announced a "Mentoring" program where we will be matching up teens with a same sex young adult with the same procedure, like the Big Brother, Big Sister program. The program roll-out will be at the UOA Youth Rally and Young Adult Conferences. As of this writing we have 66 individuals signed up for the Young Adult Conference, to be held July 17 – 19 in St. Paul, Minnesota. Our goal with further registrations is 100. Dave Rudzin and our Thirty Plus Network will be rolling out their "Ambassadors" program at the Annual Conference. Also at that conference, we are welcoming our special guests from j-pouch.org who will be holding a joint meeting with our Continent Diversions Network.

CANADIAN OSTOMY YOUTH CAMP 2003 REPORT

UOAC Canadian Ostomy Youth Camp was held June 30 – July 6, 2003 and was another success. We had 30 children from across Canada registered but 29 attended. At the last minute one child had to have surgery and could not attend. The Saskatoon chapter sponsored him and the \$450 registration fee minus \$50 handling fee will be refunded to the chapter.

We shared the camp week with the Renal children from Alberta this year. The Deaf and Hard of Hearing did not return this summer.

We had one returning ET, Carol Davis, from Toronto and one new nurse, Lana Bottomley, from Calgary. Carol was grateful for the assistance and the ladies worked well together.

Volunteers counsellors were: Kevin McHugh, Francine Small, Rob Hill, Shane Banfield and James Gow. Each bring their own special gifts to camp.

As always there are a few challenges during the week. We had one child who required much ET assistance due to recent surgery, inexperience and reluctance to be independent in appliance application and also an extreme pouching challenge. Another child had very active Crohn's disease and was not well enough to participate at the level we expect when attending camp.

There was also a child abuse issue that we became aware of and dealt with as per regulations. The account was documented by Kevin McHugh and a report of the incident has been provided for our records.

On Friday, July 4, the video that Eric Foss, video journalist from CBC, who filmed last summer, was shown to the whole group. The kids and Horizon staff were very pleased and impressed with the outcome. Everyone was in transit home when the video actually aired on CBC on Sunday, July The Canadian Broadcasting Company (CBC) video will be aired via the direct broadcasting system, on Newsworld International in the US, Europe, South America. If anyone is interested in seeing this video, keep a look out in your Television Guide for the times. We have not received any specific time for the airing.

Saturday, July 5, camp is officially over but the Camp Horizon facility has been very generous to us again and allowed all of us to stay on site for one more night in order to take advantage of cheaper air fares for the Saturday night stay over rule. We will be reviewing this practice as airfares this year seemed to be visibly reduced from last year. On Saturday morning the kids moved all their belongings to the Venture lodge where we

all stayed for the night. A bus was booked to take the children into Calgary for a shopping adventure to the mall. Everyone returned to camp for a BBQ and watched a video. Lights were out at 11:30 p.m. amidst much displeasure from the campers. The first children were off to the airport at 5:45 a.m.

We had volunteers from Calgary chapter and vendors come out to transport children to and from camp for which we are extremely grateful.

The camp was tidied and packed up by 10:00 a.m. A great time was had by all.

Tentative date for 2004 is July 5 – 11, 2004. There is no anticipated increase in registration fee.

Submitted by
Pat Cimmeck, Co-ordinator,
Canadian Ostomy Youth Camp





NEWS FROM BRAZIL

IX Brazilian Congress for Ostomates is to be held in Guarapari (State of Espirito Santo) as of September 18, 19, 20 and 21, 2003 - "Creating a Better Life"

We are organizing the IX Brazilian Congress for Ostomates, promoted by the Brazilian Society for Ostomates (SBO), to be held at SESC in Guarapari, the "Healthy City".

During September 18, 19, 20 and 21, 2003, together we shall be "Creating a Better Life".

We are indeed honored and very happy to be able to fulfill this very important task together with SBO, aware, however, of the challenges.

The main objective for this event is to gather together ostomates and their families and health professionals in order to analyze ostomates' quality of life and their inclusion within all segments of society.

We shall also be receiving Delegations from the various States; We rely on you to guarantee the success of this event.

Márcia Patricia de Araujo

President, IX Brazilian Congresso for Ostomates, and Espirito Santo Ostomy Association

Programme for Conference

18.09.03-Thursday - 17:00 - Official opening of IX Brazilian Congress for Ostomates

SBO-2003 Award
Opening Ostomy Equipment Exhibition
Dinner

19.09.03-Friday -
10:00 - 11:15

Medical Day
Round Table
-Advances and Ethical Challenges re: Genetic knowledge for Human Life
-Advances re: Ostomy Care in Brazil
-Social Inclusion

11:15 - 11:30

Coffee break

11:30 - 12:30

Debates

12:30-14:00

Lunch

14:00-16:00

Workshops
-Young Ostomates (20/40)
-Women Ostomates
-Men Ostomates
-Children Ostomates
-Health Professionals
-Ostomates families

16:00-16:30

Coffee break

16:30-18:00

Presentation of Reports re: proposals for Workshops

20:00

Dinner and Ostomates' Luau
(multicolored clothes)

20.09.03-Saturday
10:00-11:15

Human Rights
Round Table
-How to advocate a better life?
-Government's rôle x civil society: a better quality of life

11:15-11:30

Coffee break

11:30-12:30

Debates

12:30-14:00

Lunch

14:00-17:00

Exhibition and demonstration of Ostomy equipment

20:00

Gala Dinner (clothes - the 60's)

21.09.03-Sunday

10:00-12:30

Presentation of Free Themes on Ostomy

12:30-14:00

Lunch

-Free afternoon: beaches, City tour
Spring Dinner (bring your favorite flower)
Handicaps National Day



WE have published and distributed our issue no. 1, year I, of SBO Magazine. It is both scientific and informative for ostomates, health professionals, etc.

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Site: <http://www.ostomia.com.br>

If you are in South America at this time, you will have a great time with the Brazilians. They are a warm, fun loving people who work and play hard. Do join them if you have the time.

“IOA HANDBOOK” UPDATE COMING SOON!

The IOA Executive Council is pleased to advise that a “JULY 2003” revision of the IOA HANDBOOK will be sent to all Member Associations by the end of September, 2003.

Publication of this revision has been made possible by an educational grant from Hollister, Incorporated.

Editing of the HANDBOOK was a joint effort of Ken Aukett (United Ostomy Association), and Di Bracken, IOA Vice President and Secretary.

To reduce printing and shipping expenses, the HANDBOOK file will be placed on a CD ROM (disc). By using a CD ROM format Association Members will be able to store the HANDBOOK electronically, distribute it via computer to whomever in the Association needs it, and still maintain the capability of printing out as many “hard” copies desired. This will also facilitate future changes in the HANDBOOK which can be on a more frequent basis and distributed by IOA via e-mail.

From The Editor

With the mailing of this issue over 1500 people from all over the world will be receiving the IOA Today. The newsletter goes to over 66 countries through out the world. Don't forget to visit the IOA Discussion: <http://www.ostomyinternational.org/cgi-bin/dcforum/dcboard.cgi>. A place where you may post and read Ostomy related questions from all over the world. It is also a great place to meet other Ostomates.

If you have a related Ostomy report you would like to submit for the next issue, please send those to IOA Vice President: ioavicepresident@ostomyinternational.org by October 10, 2003. You may include photos in JPG format. Please send as much information about the photo as you can.