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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 PACIFIC OSTOMY ASSOCIATION (SPOA); 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



Report on visit to Cuba May 2002

Since our last edition of **IOA TODAY** I have been very busy visiting ostomates in areas of the world where life for those who have ostomy surgery is not easy, mainly due to the lack of Ostomy supplies available to all regardless of income. Let me tell you about my visit to Cuba.

I arrived in Havana on the 20th of May. My first meeting was scheduled for the 21st. After a long search and 2 taxis I eventually found the congress meeting place, which had been changed without being properly informed. I was met by the president of the local Ostomy association Dr. Lorente who to my surprise did not speak any English at all. But the presence of our NCACOA president, Martha Villez De Nieves was a great help during my entire stay in Cuba – through her we could communicate.

During my pre-congress correspondence I was informed that there would be simultaneous translation, however, unfortunately this was also non existence, which of course made it much more difficult to give my presentation. I was helped by Martha and a local scientist who spoke fair English.

On the second day I was asked to give my presentation on the work of the International Ostomy Association at 10:30, however, as the place of the convention had been changed again and it took me the best part of 20 minutes to find the place I eventually was called upon to start at 12:30 as all presentations had been delayed. (continued on page 2)

From the Vice President Di Bracken

ioavicepresident@ostomyinternational.org

Our Webmaster and myself are pleased to bring to you the third edition of IOA TODAY. As you can see for yourself, there is a great deal of interesting information from people with ostomies who are working to help other ostomates.

Our president Heinz Wolff together with Martha Vélez De Nieves, has pertinent information regarding ostomates in Cuba. Gerry Barry, the international coordinator for World Ostomy Day, has a detailed report on the plans for World Ostomy Day which is fast approaching.

(continued on page 12)

World Ostomy Day October 5, 2003

The **World Ostomy Day** is one of the most important days for ostomates world-wide. It is a day where all ostomates should act together to promote and advertise our cause. It is also an opportunity to advertise early detection and to give the general public the knowledge of our existence and that we can and do live a normal life. I also hope that the knowledge of cooperation between the medical profession and our organizations is improving in that the cooperation is getting better. I wish you all the very best for this most important day of all our organizations.

Heinz Wolff
President IOA

Editor Notes

As of this issue there are **1040 active subscribers**. This is an increase of nearly 543 since the first issue (January 2002). By the end of 2002, it is felt that we should be reaching well over 1800 via our mailing list.

In this issue besides WOD information there are reports from Martha Vélez de Nieves on her visit to Cuba found on page 2. On page 6 you may read about Arne Holte the newly elected president of NORILCO. You will also find many more great reports.

Next issue will be coming the end of October 2002 which will have information about the 2003 11th World Congress being held in Bangkok.

If you have a report that you would like to submit, please sent to ioavicepresident@ostomyinternational.org by October 10, 2002. Photos may be included in jpg format. Please include information about the photo.

WORLD OSTOMY DAY IV ACTIVITIES

Saturday 5 October 2002

"Yes, we can"

FROM GERRY BARRY – INTERNATIONAL
CO-ORDINATOR

Saturday 5 October 2002 is fast approaching and all Member Associations of IOA are reminded how important it is that we use the opportunity provided by this worldwide event. First of all it is important to celebrate the opportunity we have been given to enjoy our life that we continue to have after life-saving surgery. Then we should take the opportunity to raise awareness in our community of the benefits that ostomy surgery provides and highlight the work that still needs to be done in some countries to improve the quality of life of many of our ostomate members. (continued on page 3)

My presentation, which lasted approximately half an hour, was well received and quite a number of questions had to be answered in a very positive and fruitful way.

The next day Martha and I were invited to one of the big hospitals where we were to meet with a group of ostomates. We were met by Dr. Llorente and his group of ostomates. There were short speeches by the officials and later the ostomates presented themselves, each one giving a short history of his case.

Martha and I were under the impression that although the social conditions were rather poor and that the equipment at their disposal was of a very poor quality (one piece Chinese product) they were quite happy under these circumstances.

The same afternoon we were invited for the closing ceremony where certificates of attendance were presented and a late lunch was served.

To summarize my visit to Cuba, I'm under the impression that my time was not wasted, however difficult the situation and that it was a very wise decision of the executive committee to bring Martha with me

New contacts were made and a lot of information was gathered, which I'm sure Martha will put in her report.



IOA President Heinz Wolff riding a bull while in Cuba

I left Cuba immediately to move on to join president of the European Region, Vladimir Kleinwachter at another session arranged for ostomates.

One of the activities of Czech ILCO is organisation of rehabilitation courses for ostomates. The national organisation organizes usually a one one-week course and two weekend courses in a year. The courses are destined for all ostomates, i.e. also for those who are not members. In addition larger local clubs prepare rehabilitation courses for their members. Vladimir Kleinwachter, the European president reports on this event in this newsletter.

I left this interesting experience with the knowledge that we as an international organization have much work to do to ensure that all ostomates regardless of where they live have access to quality, affordable Ostomy supplies on a regular basis. We, as individual countries, must work together to achieve this.

I will be visiting two conferences in North America in August - the UOA Inc. conference in Philadelphia and the UOA Canada conference in Halifax. If you will be in attendance, please introduce yourself to me. I will be happy to speak with you about the work of the International Ostomy Association.

All the best
Heinz Wolff
IOA President



Ostomy group meeting in Cuba.

CUBA REPORT

May 20-25, 2002

Prepared by: Martha Vélez de Nieves

On May , 2002 President, Heinz Wolff and I, visited La Habana, Cuba to attend to the "5to. Congreso Latinoamericano de Coloproctologos." Dr. Francisco Llorente Llanos, President of "Seccion de Atencion a Ostomizados" (S.A.O.) invited us to this congress.

The first day there was a confusion as the Congress was changed from Centro de Convenciones to Centro de Eventos ORTHOP and we were not aware of this situation. After making various calls, the bus arrived at the Hotel Copacabana to pick me up and transfer me to the event. I requested the driver to pick-up Heinz at the Habana Melia and he refused, saying that he already stopped there.

For Heinz's surprise, Dr. Llorente did not speak English and later on we discovered that the e-mails he sent were translated by an English Professor.

The Congress did not have simultaneous translation, but there was a translator who helped Heinz with his presentation. Heinz made a good presentation at the Congress. Many of the doctors were interested in our organization. We handed out copies of our brochure and of coloring book "Ale Tiene una Ostomia". I have requests from many doctors and nurses who need ostomy material en Spanish.

During the afternoon, I stayed at the Congress to participate in a round table presentation of S.A.O. made by Dr. Llorente, ostomy members and nurses. It was quite interesting to know that they are a very well organized group. They have social workers, doctors, and nurses involved in their group. I was very impressed by a remarkable story made by a member of S.A.O. on her recovery after surgery and how this group helped her.



IOA
Online



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

The next day we took a Taxi and visited “ Hospital Clinico Quirurgico Universitario Comandante Fajardo”. Members of the SAO Association received us with flower arrangements. They expressed how happy they were about our visit. The hospital was in a poor condition. The surgical equipment is very old and they have many things that need improvement. The ostomy supplies they use come from China, packed in boxes of 100 and with a cost of approx. 4.00 Cuban pesos. It is a one piece equipment, transparent bag. This is the only equipment they know. Heinz and I looked each other and we didn't know what to say. After a while, Heinz came up with this spectacular answer and I quite “Look, if this is what you have, it is okay, as there are some places in the world, where people don't have anything to use”. We both smiled and they were satisfied. Dr. Lorente is one of those doctors who really care about his patients. We met with Ivon the nurse in charge of ostomy patients, and she demonstrated great interest in becoming an ET Nurse. We need to find out some information for her on this matter.

In general, I would say that we now have a complete story of how the Cuban ostomy association works and how difficult it is to have an ostomy in Cuba. People are very poor; earning approx. 200 Cuban pesos a month which comes out to approx. US\$10.00. We were charged in US Dollars for all our expenses. They claim that US\$ is the same as Cuban pesos which is not true. (1 Cuban Peso = US\$25-27) The city looks very poor, hotels are very luxury, but as you step out of it, the story is completely different. For me, it was a great experience.

WORLD OSTOMY DAY IV ACTIVITIES

(Continued from page 1)

As I have previously advised it is planned to have a chain of e-mails go around the world and as the day approaches I will be sending out a list of e-mail contacts and times to enable countries involved to send progressive greetings and messages, starting with New Zealand.

A number of countries have sent in their plans for WOD 4 by returning the “Advice of Participation Form” which was sent out with the minutes of the March Executive Meeting. Unfortunately there was a delay in circulating those minutes and some countries have not had the opportunity to respond. However it is not too late. Entries can still be sent in. Electronic copy of the Participation Form is available through my email. (Generally the national association of a country should reply. Local chapters/associations should join with their national associations if they wish to become involved. If this is not possible please contact me before returning a Participation Form.)

The “Coloplast Merit Award” will again be made in 2002 for the best WOD Project. Judging will be based on the events of the day. The judges will consider the following aspects:

1. The degree to which the entry fulfills the aims and objectives of WOD.
2. The level of innovation and enterprise.
3. The level of quality relative to size/resources of the association.
4. The degree of impact nationally, including press coverage.
5. The suitability of proposal/activity for other countries, particularly emerging nations.

Apart from the Award itself there will be a first prize of \$US4000 and a second prize of \$US1000. Only IOA Member Associations or Member Countries are eligible to enter for this award.

I will be asking all participating associations or countries which enter the Coloplast Merit Award to provide details of the actual activities and outcomes achieved on the day. I will try to make this as easy as possible by providing an electronic form to be completed which will show the matters which will be taken into account by the judges.

All WOD 4 arrangements, collection of material and questions will be co-ordinated by myself.

My contact details are –

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EARLY PLANS RECEIVED FROM COUNTRIES PARTICIPATING

(I apologise if editing for publication has changed any important details)

Australia –

Australia has decided, following a suggestion by Heinz Wolff, to launch the “Australia Fund” to provide assistance to ostomates in other countries who need support. The establishment and collection of contributions for this fund will be Australia's project for WOD.

A collection target of CHF 50,000, to be achieved by WOD, has been set to reflect the theme "Yes we can". Publicity for WOD in Australia will, in part, be built around the plans for use of the funds.

Brazil (sbo) –

Considering that presidential elections are being held on 06/10 this year we are planning 2 phases for WOD activities.

On 5 October we are delivering to each candidate (4) a copy of a document entitled Platform for Public Policies concerning Ostomates. This document will be delivered to each presidential candidate and offers proposals for political policies concerning Ostomates in areas of health, employment, rehabilitation, and transportation.

We will be registering the event by means of dated photos. There will be simultaneous elections held also for State Governors and the President of each Ostomy Association will have a copy of a paper entitled "State Platform - Assistance for Ostomates" which they will deliver to candidates for Governors, registering the event by means of dated photos.

We will hold a meeting in Rio on 10 to 13 Oct. The 23 Presidents of respective Ostomy Associations to evaluate the delivery of our document: Each State will close With the WOD activities on 31 October having regard to the theme "Yes, we can":

Canada –

Chapters throughout Canada will be setting up displays at local Hospitals, Suppliers outlets, shopping malls. There will be several news articles in local papers, Some T.V. interviews, Mayors of our Major Cities in Canada will be proclaiming October 5, 2002 World Ostomy Day. We also will be obtaining a Proclamation from the Prime Minister of Canada proclaiming October 5, W.O.D.

At a major Hospital in Toronto we will be having a rally for WOD. We will also be having a Banner with WORLD OSTOMY DAY, OCTOBER 5, 2002. This will be hung in the front lobby of the Hospital. We will have a small program that day and Hollister Canada and Conva-Tec and Coloplast reps will all be present. Conva-Tec will be giving away cash prizes to what ever UOA Chapter across Canada did the most to proclaim WOD. Hollister will be making up posters for us to be sent to every chapter and supplier and hospitals and E.T's across Canada.

Czech Republic –

We plan to have a festival World ostomy day, whereupon we want invite deputies of top, regional and local state agencies, chairman of federation invalid, medical public, directors general of Czech wireless and television and editor-in-chief of the best known daily. We will ask President CR Mr. Vaclav Havla, a former temporary ostomate, to take over patronage of WOD. We will take part in e-mails connecting all the ostomy world. Our clubs will arrange local jubilees for WOD.

Expatriate Ostomates of the Costa Blanca (Spain)

The principal activity of our international group is likely to be a Grand WOD Celebration Garden Party for ostomates, families and guests to be held on this day in Jávea in an EOCB member's garden. The question of non-member invitees has yet to be settled but we do intend to invite representatives of Spanish groupings in the Region in order to establish links wherever possible.

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**Discussion
Forum**



In advance of the day, we shall submit a short statement or 'letter to the Editor' to the local/regional press under the heading of 'Yes, we can'. This will inform readers as to the aims and objectives of WOD and of the existence of the IOA and of the EOCB.

There is just a possibility that a member in the southern part of our region will put on a jazz concert intended primarily to thank the local hospital for the good care that he

received. Opportunity would be taken to make an announcement introducing WOD and the 'Yes, we can' theme. The venue for this has yet to be settled.

Germany (Deutsche ILCO) –

The Board of Deutsche ILCO did recommend all 300 local/regional chapters to motivate key persons on the local/regional level (e.g. Mayor, Chief Surgeon of the Clinic) to

organize a **WOD-Birthday-Reception** to honour Deutsche ILCO and the 30th Anniversary of Deutsche ILCO. If not possible in this way the local/regional chapter should organize this reception. All key contact persons of the local/regional chapter and representatives of the local/regional media will be invited. It is planned to intensify the interest of the local/regional media for this reception by cutting a **WOD-Birthday cake**. The members of the local/regional groups are invited to spend for this event cakes with a WOD-Birthday decoration. The best-decorated cakes will be published in the journal ILCO-PRAXIS.

A WOD poster (see enclosure) and information material will sent to German coloproctological clinics and coloproctologists as well as to pharmacies to promote Deutsche ILCO and WOD.

Philippines –

Activities for and by members of the Ostomy Association of the Philippines will be held on World Ostomy Day 4. Press releases will be issued before the day itself, to make the general public aware of the event.

Ostomy Workshops to be held by the Society and the Department of Health in four provinces as well as four private hospitals in Metro Manila in July, August and September, will also be used to promote awareness about ostomate needs and welfare, set up local ostomate groups and create more awareness about WOD.

Since the 4th Asian Ostomy Association and the 7th House of Delegates Meeting will be held in the Philippines on October 23-26, there will be a culminating activity for World No Tobacco Day. This will be held during the Fellowship Night on October 26. Performance numbers by Filipino and, we hope, foreign ostomates attending the Conference, will be held during the Night. At present, OAP members are already having regular rehearsals for this.

Russia (Astom) –

We will provide information about ostomy matters to the mass media and will display details of WOD on the web site of "ASTOM".

There will also be a meeting of the members of Organization "ASTOM" and the release of an information page and distribution among of the ostomy patients.

We will hold information sessions for all Organizations to tell them about ostomy patients of Russia and provide formal notice of Government of Moscow and Russia about WOD.

Ukraine (Odessa – ILCO) –

Because there is an absence of a stoma-care environment in our country (stoma-consulting rooms, stoma-nurses, stoma-theraputists and etc.) most of stoma-patients have not any information about stoma care, have neither stoma accessories nor money for buying them. They even don't have any help from anybody!

In spite of absence the normal life conditions of Odessa Region for stoma-invalids, the main aims of "Odessa-ILCO" this Day will be to give them information about International Ostomy Association activity. In order to do this we are planning to make the common meeting of the "Odessa-ILCO" and to show our members "IOA Magazine" (we have now 3 issues of it and book "YES, WE CAN") and to show them via Internet web sites of the most of IOA members and to read and translate them the contents of these sites and issues (many of our people don't know English). This information will show our people "Ostomy World" and help them to understand that there are many the same people all over the world and the most of them can say "YES, WE CAN".

We'll organize direct contacts and phone-conversations with ILCO organizations in Kiev, Moscow and St-Petersburg for exchange experience.

There will be a sport competition on other kinds of sport, especially – swimming in the Black Sea as well as fishing and relaxation on evening – dance and sing our anthem.

United Kingdom –

World Ostomy Day on 5 October 2002 will be capitalised upon by the three ostomy

groups in the UK and others, as in the past. The three ostomy Patient Support Groups (PSGs), together with RCN Stoma Care Forum (SCF), WCET, Association of Coloproctology - Nursing Chapter, as well as the ostomy manufacturers and suppliers, will join together to promote the need for greater ostomy awareness and support for ostomates, their carers and the public in general.

To do this we will have a high profile "Roadshow" centred on a selection of key venues around the UK and Ireland to get the message across. Through this means ostomates and those closely associated can demonstrate, to the press and others cohesiveness in caring for one another.

The specific objectives are –

- 1) To raise awareness amongst ostomy patients.
- 2) To encourage the public in general to find out about bags, bowels, bottoms, bladders and stomas together with the under-lying illnesses.
- 3) To support the manufacturers and distribution companies in reaching their clients.
- 4) To get the message out that ostomates are able to live a complete and purposeful life.
- 5) To spur the media to highlight the medical advances and normalization of patients' lives, and that the subject should not be treated as taboo.
- 6) To promote the research that is being conducted into the causal illnesses.

Target audiences will be Ostomy patients, Medical and Nursing professionals including GPs, Carers, the press and the general public.

USA

There are five (5) Ostomy Awareness Seminars scheduled for the month of October 2002.

The sites include Philadelphia PA, Salt Lake City UT, Miami, FL, St. Louis MO and one other.

Promotion will focus on the need for ostomy awareness and education at the community level and that this event is in celebration of World Ostomy Day 2002. These seminars will be promoted through all channels in the healthcare community, local newspapers, and national web sites.

The purpose is to update members of the medical healthcare community on anatomy/physiology and psycho-social support for patients undergoing bowel or bladder diversionary surgery. The target audience will be Staff nurses, Social workers and/or discharge planners, Nursing and medical students, HMO administrative representative (care manager), Local ostomy suppliers and distributors, Ostomates in the general area.

This is a community effort saying, "Yes, We Can".

11th IOA World Congress

October 26-30, 2003

Bangkok, Thailand



**Profile of
Arne H. Holte**

E-mail arnehol@online.no

I'm 58 years - had an ileostomy which I got in 1974 due to Ulcerative Colitis. I've been a member of NORILCO since then. I became president of my local chapter in 1979 and held that position until 1996. In 1994, I became a member of the national board, and in 1996 was elected as vice president. I have been elected to the presidency this year – 2002.

Nationally I've been mainly working with Public Relations and visiting service (have lead this service for the four last years).

I am married with two sons and three grandchildren. I live in Kristiansand - on the south point of NORWAY

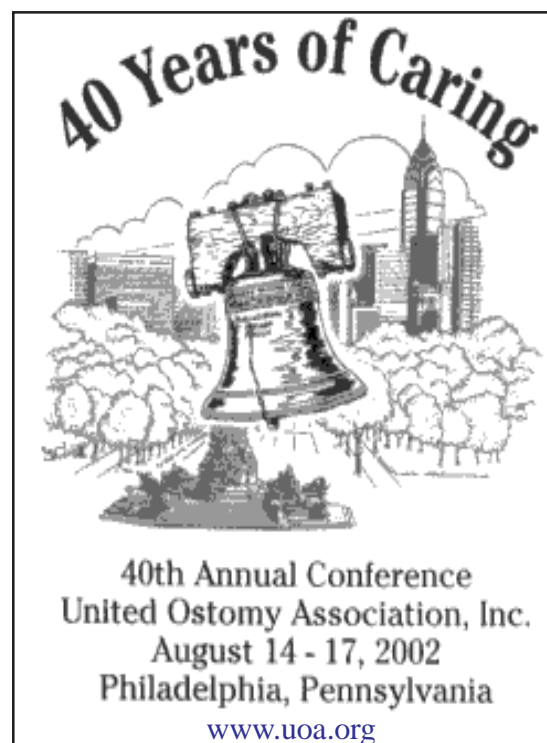
I have participated in several international events such as the congresses in Calgary and Amsterdam, the EOA-meetings in Venice and Copenhagen as well as a number of Nordic meetings.

My dreams for NORILCO in the future is that "whenever anyone hear the word ostomy (or internal pouch) they shall say: **NORILCO**. Internationally I dream about a situation where the developed countries in "our" family have established a situation where we know what countries need help - and what countries can give it.

In fact I feel it's a shame that we have not reached that situation yet.

Best to you all from

Arne



International Co-operation

A presentation by Arne Holte, the newly elected president of NORILCO, at the 18th UICC International Cancer Congress, which took place in Oslo 30 June to 5 July 2002.

My name is Arne Holte, I come from NORILCO, The Norwegian Ostomy Association – the association for persons in Norway who have had an ostomy operation, or an intestinal or urinary tract diversion. NORILCO is one of the seven patients' associations affiliated to the Norwegian Cancer Society.

I am going to tell you a little about the patients' associations' involvement abroad, especially NORILCO's, and how we co-operate with various associations, groups and individuals in other countries.

But, first of all, a little about NORILCO itself: NORILCO has more than 5000 members in 22 local chapters throughout Norway. About 8 – 9000 persons in Norway today have had an ostomy operation, and have to live with a stoma or reservoir. So the percentage organised in NORILCO is very high – one of the highest in the world.

Most of the seven affiliated patients' associations co-operate in some way or other with comparable associations in the other Nordic countries. Meetings are arranged for exchange of news and opinions, and to develop social contact and friendship with other persons with the same handicap. Most of the associations also participate in European congresses and meetings, and in different forms of global co-operation.

The Norwegian Society for Laryngectomees – for persons operated on for throat cancer – co-operates with a doctor from Croatia who is trying to start a society for throat cancer patients in that country. This doctor has visited the Norwegian association.

The Norwegian Breast Cancer Society co-operates with the other Nordic sister organisations. Conferences are arranged every second year for exchange of information and experiences. The society is a member of Reach to Recovery – an international help organisation under the auspices of UICC. This organisation holds conferences once every three years.

The Norwegian Breast Cancer Society has also established contact with a large hospital in Ivanovo, in Russia, where aids like wigs and prostheses are in very short supply. The society collects this kind of equipment in Norway and sends it to the hospital in Ivanovo. In the long term, it is intended to establish a visiting service in Ivanovo, which may help to raise the quality of life of women treated for breast cancer at the hospital there. The Norwegian society has invited and paid for the woman director of the hospital in Ivanovo to spend some time at a hospital in Norway as an observer.

Coming together

Representatives of NORILCO attend Nordic Meetings – organised by the Nordic Ostomy Association. We also take part in European meetings and world congresses. A Nordic meeting is arranged every year, in each of the Nordic countries in turn. The meetings have in recent years developed into true working gatherings, with the participants working partly in groups and partly in plenary sessions. A deliberate effort is made to develop things of common interest – for example, advice and guidelines, video tapes, marketing material, brochures et cetera.

A World Ostomy Day (WOD) is arranged every third year. Attention is drawn the world over to persons with a stoma or reservoir. NORILCO's 22 district chapters, established throughout the country, take part in this effort through various types of arrangements like courses, stands etc.

Bad conditions

The situation for persons with a stoma or reservoir varies considerably in different parts of the world. In many countries these patients have easy access to the aids they need, in other countries such equipment is completely lacking. This is the background for most of my talk speech.

Ten years ago, when NORILCO arranged a European meeting in Bergen Norway, a few participants turned up from Russia, two of them from St. Petersburg. They told of the difficult and undignified situation for ostomy operated persons in this large city in western Russia.

NORILCO's Board decided to try to help ostomy operated persons in the city on the banks of the river Neva. Our very first priority was to collect stoma and other medical equipment to send to St. Petersburg. Our first consignment reached its destination in mid-June 1993. Since then, NORILCO has sent many tons of necessary stoma and reservoir equipment to our sister association, ASSCOL in St. Petersburg. We have also collected enough money to buy a small van, which is used to distribute the equipment. In co-operation with Norwegian nurses, we have arranged two courses in St. Petersburg for Russian nurses and voluntary workers from ASSCOL – almost 60 in all. One of the courses was in co-operation with the Norwegian section of WCET.

As well as the stoma and reservoir equipment we have also dispatched medicines, surgical equipment, breast prostheses and incontinence devices. In addition, Russian surgeons have visited Norwegian hospitals. As I have said, the situation for the six to seven thousand ostomy operated patients in St. Petersburg has not been the best by any means. And the hospitals, and the equipment available to the doctors, are not what we are used to in Norway.

Some years ago we arranged a tour to St. Petersburg for about 25 Norwegian patients with a stoma or reservoir. We were guided by members of ASSCOL, and we had a most successful social get-together in an atmosphere of fellowship and understanding.

Great differences

There is a tremendous difference between Norway and St. Petersburg. This difference presents a problem in itself, because a Russian ostomate is unable to understand the everyday situation for ostomy operated patients in Norway. To give you some idea, they say "I hear what you say, but I just don't understand it". When we tell them about our hospitals, our doctors, our equipment, our social security rights – all this is so far-removed from their own everyday experience that they may soon become totally uninterested. For them the way ahead is long and steep.

In Norway – and in most other countries – we know that, if you are to have a good life after a stoma operation, the stoma must be constructed properly. In simple words, it has to be placed where the plate and the pouch can be easily affixed to the skin. This means that the stoma must be constructed at a site on the abdomen without any folds of skin, so that neither faeces, urine nor air can leak out. If such leaks occur, it is impossible to live a normal life. When we arranged courses in St. Petersburg we saw grotesque examples of stomas placed deep in folds of skin, which unavoidably leads to serious leakage problems, and inevitably, reduced quality of life. Probably the only expectation for these patients is a life spent in isolation.

One of the aims with our first course was to teach doctors and nurses to choose the correct placing of the stoma.

Another serious problem connected with our activities in Russia is the language barrier. Unfortunately, only very few persons in St. Petersburg speak English, though the situation is improving. Here most of the patients who have had an ostomy operation are quite old, which can make the situation even more difficult. We have to have an interpreter, preferably Norwegian/Russian.

What is most important in the international efforts?

Here we have to distinguish between acute help, or short-term efforts, and long-term co-operation. First, a little about the short-term effort. As I have already said, there are between six and seven thousand ostomy operated persons living in St. Petersburg. Many of these get help and bandages from a stoma clinic that receives a some financial support from the city council.

NORILCO's consignments of equipment go to ASSCOL, which helps almost 500 persons who do not receive any other form of assistance. This makes it necessary to carry on with these consignments – and NORILCO will do just that. We shall continue to collect surplus equipment from all over Norway. All NORILCO's 22 district chapters have appointed a contact person to be responsible for sending the equipment to our office in Oslo, from where it is forwarded to St. Petersburg.

We use an international transport company that has scheduled service to St. Petersburg. This – in addition to properly filled in customs declarations – is absolutely essential to ensure quickest transport to Russia. Even so, major problems may occur at the border.

Other co-operation – establishment of voluntary organisations – why and how?

In the long-term it is very important to help other countries to build up voluntary organisations, which is what the patients' associations are. To my knowledge, unlike in Norway, where many of us are members of a sports club or suchlike without being particularly active in this connection, people in Russia are not used to joining a voluntary organisation – there is no, or very little tradition of this kind. Often membership of such an organisation only leads to costs and extra work. Communal efforts, in the form of lotteries, clean-up campaigns and waffle making are examples of what we take on in Norway when we join a sports club, for example. Perhaps many of us became members because our children take part, or once took part, in the actual sports activities.

As I understand it, this is rare in Russia. Why should you pay to be a member of something that does not give specific benefits? Moreover, many ostomy operated patients in Russia cannot afford extravagances of this kind.

In spite of this, NORILCO – together with others – will try to do what we can to build up organisations like ASSCOL in St. Petersburg. For the time being, we must be glad that ASSCOL has its 500 members. A drop in the ocean, perhaps – OK, so it is – but we still think it important to do what we can to help. And we hope that many others will do the same through sister organisations et cetera. If many organisations throw stones into the pond, each will make its little ring, and gradually the rings will flow into each other.....

In NORILCO we are fully aware of the great difference between Norway and St. Petersburg in terms of money and other resources. Not least, there is an enormous difference in the health services. So it is crucial to make absolutely sure at the courses that we do not frighten away or totally confuse the participants. "We hear what you say, but you are not talking about us". Important key words are humility and empathy.

11th IOA World Congress

October 26-30, 2003

Bangkok, Thailand

Lots of challenges

At the courses we must try to find out where the challenges differ and where they are common to the two countries. We must acknowledge that we do not know enough about the situation in St. Petersburg. We must encourage active participation, which may be difficult because many people are often reluctant to talk about their personal problems. It is vital that the leaders of the courses show that they understand the situation, so as to gain the trust of the participants and get them to make an active contribution. Otherwise, the courses may be of no value at all. At our course in June 2002 we paid this aspect great attention.

How does one go about organising a course in a large city like St. Petersburg. The city has a lot of hotels. Some are good – and expensive. Others are not so good, in fact very poor by ordinary standards – but cheap. Luckily there are several acceptable tourist hotels used by western travel agencies. We used one of these hotels for our last course. Almost everything was arranged through a Norwegian travel agency. And I am happy to say that we do have close contact with the Norwegian general consul in St.Petersburg.

And what about financing? NORILCO's activities in St.Petersburg are supported by The Norwegian Cancer Society – and also from the Norwegian Foreign Office.

So – is there any sense in participating in international co-operation?

Obviously such participation is meaningful. I would put it even more strongly. We who, in many ways, have relatively good resources – both as a nation and as an association – have an obligation to help. Some nations can help on a broad basis – but all can help as well as they can.

The Nordic, European and international co-operation through regular meetings is important and necessary, but direct contact with another country, another association, is crucial. Many countries in western Europe have direct contact with an association in another country – this is often called twinning, which means that an association in one country has a twin in the other country. NORILCO's twin is ASSCOL in St. Petersburg.

This twinning must be better organised internationally. We have databases that tell us how much equipment has been sent to countries in need of it. Even so, I feel that these bases are not updated properly because of deficient reporting. This can lead to more than one nation is sending equipment to the same country.

You get so much back from taking part in international co-operation. You get more insight into other people's problems, and so much gratitude from people whose situation is far worse than your own. The fellowship you experience with people with the same handicap as your own is very satisfying.

The principal objective in this kind of work is to help to build up viable, voluntary organisations operated by –

and for – patients with a stoma or reservoir. On the road to this goal, we must not forget that acute help – the dispatch of bandages and equipment – is also of vital importance.

NORWAY AND ST PETERSBURG

Still a long way to go!

Norway and St.Petersburg, Russia. About the same number of inhabitants and also nearly the same number of ostomates. But that's it. Nothing more seems to be equal – at least for people with an ostomy. As we in Norway just have to pay a minor amount for our appliances and can choose between different types and numbers, there is a tremendous lack of bags and wafers in St Petersburg that we in Norway have no problems obtaining. Also in the way of organizing and belonging to an organization seems to be different.

Trying to make those gaps smaller was one of the reasons for NORILCO, Norway's latest two-days course in St.Petersburg. The first day Knut Ellingsen was responsible as we dealt mainly with how to organize and run an organization. Eager participants were members of our twin-organization, ASSCOL and nurses from the Stoma-center run by Rafael Ochanski.



A board member of ASSCOL expresses his viewpoint.



From left Rafael Orchanski, a young doctor who spoke a little Norwegian and Vladimir Artemiev - ASSCOL's new president

Next day Arne Holte, newly elected president of NORILCO with many years of experience on visiting service, lectured about this service with a hope of obtaining the same sort of service in that huge city on the banks of the river Neva.

Even if it's a long way to go, we learned that Asscol is organized in a way that's not so very far from our. We also learned that they have something which seem to be a sort of visiting service. 17 information personnel in different districts answers telephone calls from anxious ostomates or relatives. They also hand out appliances given by NORILCO. As ASSCOL helps its 450 members in this way, one can imagine that this is far to little. Fortunately there is also a stoma-center which helps about 3000 ostomates a year. Nevertheless there are some 2000 - 3000 ostomates that have none – or insufficient help.



From the right Arne Holte, Elizabeth Hermansen, Jorunn Movold and the Russian interpreter Vera Diakouova

Photograph taken by Knut Ellingsen who was head leader of the seminar.

For my part I hope for improvement in not too long a time - and that our course was a contribution to that. Among other feed-back talks we had with a nice lady from the Heath Department in St.Petersburg gave us some hope of that. In the meantime NORILCO will continue to send surplus appliances two to three times a year. We will also continue our commitment including supporting ASSCOL's work on visiting service, on their effort to get more help from the city's authorities and their daily work among ostomates. In NORILCO we are very pleased with the good contacts and help we have got from the Norwegian general consulate, from Tania Chikova from Convatec, from Rafael Orchanski from the Stoma-center and others in St.Petersburg.

Arne Holte, President NORILCO

News from Kyoshi Kasahara in Tokyo, Japan

I have recently updated JOA HP, and would like to introduce it to you in the coming IOA Today. This updating includes the report of our 14th National Conference held in June 1-2, that of 1st ASSR Congress held in April, etc..

<http://www.norma.netne.jp/~JOA/eng>

The latter Congress (where ASSR means Asian Society of Stoma Rehabilitation) is worth to note that it is the first trial where medical professionals in Asia meet together and discuss on not only stoma care, but on ostomates' rehabilitation into the community as well as enhancing their QOL. It will also have interrelationships with activities of AOA and IOA in future; the next ASSR is planned to be held in Bangkok in October, 2003.

Best Wishes to you all

Kyoshi Kasahara

Editor of JOA Homepage

wx5k-kshr@asahi-net.or.jp

REHABILITATION COURSES IN THE CZECH REPUBLIC**REPORT BY VLADIMIR KLEINWACHTER, PRESIDENT EUROPEAN REGION**

One of the activities of Czech ILCO is organisation of rehabilitation courses for ostomates. The national organisation organizes usually one one-week course and two weekend courses in a year. The courses are destined for all ostomates, i.e. also for those who are not members. In addition, larger local clubs prepare rehabilitation courses for their members.

The first spring rehabilitation course was organized from 5 to 11 May by the Brno club in a small village Ramzova located in the highest mountain range in Moravia - Jeseníky. The course was attended by 40 ostomates, some of them were accompanied by family members. For the health care were responsible Dr. Josef Vseticek and a stoma therapist Dragica Krenkova, who is also an ostomate and leads the Brno club. During the whole week we had at disposal a masseuse and a yoga instructor, who conducted every day a morning and afternoon exercise.

The whole week the weather was beautiful so that we could make tourist trips either to the mountain ridge or to the near romantic towns and villages. An excursion was made also to the spa Jesenik, which was founded in the 19th century by G. Priessnitz.

In the evenings we had usually lectures about the stoma care. The representatives of the three main manufacturers of appliances operating in the Czech Republic, ConvaTec, Coloplast and Dansac, came to give us information about novelties in their production.

You can feel the good mood of the participants from the accompanying pictures.

Vladimir Kleinwachter, President European Region



Participants of the course in front of the hotel.



Celebration of the 80th birthday of the chairman of Czech ILCO Dr. Oldrich Capka.



The monument of G. Priessnitz, founder of the spa Jesenik.



Presentation of Coloplast.



On the top of the mountain Kepnik.

(continued from page 1)

Stuart Schaefer has provided me with some interesting statistics for the IOA Web and I have included the chart of the top 30 of 76 countries for the month of June 2002. As you can readily see there is excellent representation from around the world. I have enjoyed responding to the many questions that have come to me via the Website and we are all pleased that as an international organization we have been able to help.

Top 30 of 76 Total Countries (For the month of June 30, 2002)							
#	Hits		Files		KBytes		Country
1	50413	35.46%	29593	30.36%	215830	32.66%	US Commercial
2	45552	32.04%	32177	33.01%	208073	31.49%	Network
3	26811	18.86%	20807	21.34%	125495	18.99%	Unresolved/Unknown
4	3218	2.26%	2286	2.35%	16004	2.42%	Canada
5	2734	1.92%	2060	2.11%	12863	1.95%	Australia
6	1689	1.19%	1416	1.45%	9471	1.43%	United Kingdom
7	1610	1.13%	1416	1.45%	10842	1.64%	US Educational
8	1596	1.12%	852	0.87%	7238	1.10%	Spain
9	1243	0.87%	815	0.84%	9944	1.50%	Netherlands
10	969	0.68%	727	0.75%	4890	0.74%	New Zealand (Aotearoa)
11	785	0.55%	589	0.60%	3294	0.50%	Non-Profit Organization
12	683	0.48%	584	0.60%	3950	0.60%	Japan
13	491	0.35%	474	0.49%	3170	0.48%	US Government
14	328	0.23%	302	0.31%	1986	0.30%	United States
15	270	0.19%	267	0.27%	3086	0.47%	Belgium
16	236	0.17%	90	0.09%	696	0.11%	Singapore
17	234	0.16%	210	0.22%	993	0.15%	US Military
18	228	0.16%	203	0.21%	1093	0.17%	Italy
19	221	0.16%	147	0.15%	1358	0.21%	Czech Republic
20	220	0.15%	190	0.19%	1428	0.22%	Finland
21	201	0.14%	194	0.20%	1152	0.17%	Portugal
22	184	0.13%	135	0.14%	1555	0.24%	South Africa
23	181	0.13%	111	0.11%	721	0.11%	Malaysia
24	154	0.11%	120	0.12%	1067	0.16%	Greece
25	139	0.10%	138	0.14%	1025	0.16%	Slovak Republic
26	132	0.09%	131	0.13%	1249	0.19%	Switzerland
27	130	0.09%	122	0.13%	805	0.12%	Ireland
28	124	0.09%	116	0.12%	701	0.11%	Mexico
29	115	0.08%	112	0.11%	909	0.14%	Denmark
30	112	0.08%	97	0.10%	711	0.11%	Poland

One of the interesting contributions in this issue comes from Arne Holt and is his presentation given at the UICC International Cancer Congress in June of this year. As some of you know the International Union Against Cancer (UICC) is the only global cancer organisation with members and activities covering all aspects of cancer control. Founded in 1933, UICC is an independent, international, non-governmental association of 291 member cancer fighting organisations in 87 countries.

UICC's purpose is to promote awareness and responsibility for the growing global cancer burden; to take effective action to prevent and reduce cancer incidence and mortality; to improve the quality of life of cancer patients and their families, and to build the capacity of its members and partners to meet local cancer control needs.

Members include voluntary organisations, cancer leagues and societies, cancer research and/or treatment centres and institutes, cancer patient associations and, in some countries, Ministries of Health. Members benefit from programme services and activities as well as special interest networks. IOA became a member in 1998. John Cardosa, President of the Asian region, is IOA's liaison to UICC. John is also a member of the steering committee of the COPES programme (Cancer Organization Public Education Patient Services).

UICC has a most interesting Website at <http://www.uicc.org/>

We are sending you independently a copy of the Asian Ostomy newsletter edited by Dato John Cardosa. This gives us all motivating information as to what is happening in the Asian region. (continued on next page)

The Asian Regional Meeting will be taking place in October 2002 in Manila and I look forward to meeting those able to attend.

Look for our next edition of IOA TODAY at the end of October. We hope to have specific information regarding the IOA World Congress in Bangkok, Thailand.

I hope that you will find this edition of IOA TODAY informative and appealing. I thank you for your support and interest in our organization. Wherever you are in this interesting world of ours, I hope that you are well. Take good care and stay safe.

4th ASIAN OSTOMY ASSOCIATION & 7th HOUSE OF DELEGATES

The Philippines hosts the 4th Asian Ostomy Association Conference and 7th House of Delegates Meeting on October 23 to 26, 2002 at the Century Park Hotel. With the theme "Building Bridges through Ostomy Care," the conference will cover a wide spectrum of topics directly and indirectly related to stoma and ostomy care.

The conference hopes to bring together ostomates and their caregivers from the different parts of the globe to interact and exchange ideas and experiences with each other and develop new insights from these.

The patroness of the conference is President Gloria Macapagal-Arroyo and honorary chairman is Health Secretary Manuel M. Dayrit. The overall chair is Dr. Romeo Gutierrez; co-chair is Ms. Aurora Valenzona, president of the Ostomy Association of the Philippines; and the secretary general is Dr. Alberto Roxas. International Advisers are Capt. (Ret) Heinz Wolff, Ms. Dielwen (Di) Bracken, Mr. John O'Neill, Ms. Brenda Flanagan and Dato' John D. Cardosa.

For delegates who register on or before July 31, 2002, registration fee is USD 50. After July 31 registration fee is USD 80. Full registration entitles a delegate to a conference bag with inserts; attendance to all conference activities and social functions; complimentary tour/shopping; and lunches, snacks, and official dinners. Century Park Hotel, venue of the conference charges USD 70 per night single room with breakfast and USD 37.50 per night per person, twin sharing with breakfast.

For inquiries, please contact the secretariat at the Philippine Cancer Society, 310 San Rafael St., San Miguel, Manila Philippines 1005 P.O. Box 3066 with telephone number (632) 7333485; telefax (632) 7352707. Log in at www.philcancer.org/ostomy or send an e-mail at 4thaoa@pcsi.com.ph.

29th Federation of New Zealand Ostomy Societies Conference Cophorne

Plimmer Towers Hotel, Wellington 9th to 11th August 2002

Contact: kotuku.michelle@paradise.net.nz



<http://www.ostomycanada.ca/>

COME SEE US IN HALIFAX AND CATCH THE WAVE

If you are in the area of Halifax, Nova Scotia, the United Ostomy Association of Canada would like to invite you to attend our Annual Conference. The conference Hotel is THE WESTIN NOVA SCOTIAN and the dates August 15 – 17th 2002. As well as offering a number of different topics for those who have had ostomy surgery, we are broadening our scope of sessions this year.

For the first time in Canada, under the leadership of Scott Warren, there will be sessions for ostomates between the ages of 20 and 40 years of age. Scott was present at the IOA 20/40 Focus in Hamilton and decided that he wanted to offer sessions to get the young people interested in attending conference.

The first session will be an OPEN FORUM. This is your opportunity to LET IT ALL HANG OUT, where you can discuss issues of your choice in the detail and length you desire. Another session is SEXUALITY AND THE OSTOMATE aimed specifically at the 20 / 40 age group.

The Spouses and Partners have programmes to suit their needs. They open with an information night letting participants know what to expect from the conference. On Thursday there will be a walking tour of the Waterfront – a great location. Rap sessions will be of importance as discussion will center around the concerns and interest of those in attendance.

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4TH MEETING OF OSTOMATE ASSOCIATIONS FROM CENTRAL AND EASTERN EUROPE

Vladimir Kleinwachter
*PRESIDENT EUROPEAN
OSTOMY ASSOCIATION*
europeanregion@ostomyinternational.org

31 May - 3 June 2002, Kaunas, Lithuania

GENERAL

Representatives of ostomate organisations from Central and Eastern Europe meet every 2-3 years. Initially this regional meeting took place in St. Petersburg (Russia) in 1993. However, many associations from this European region were not yet members of IOA and thus the attendance was limited. In 1995 1st Meeting was organised by Czech ILCO in Brno (Czech Republic) in parallel with a medical International Congress of Coloproctology. The co-operation between physicians and ostomate organisations is quite essential in this part of Europe and this arrangement makes possible the participation of physicians at the ostomate meeting. This meeting was attended by delegates from 5 countries. 2nd Meeting took again place in Brno in 1997 together with a coloproctological congress; delegates from 7 countries were present. The 3rd Meeting was organised by POLILKO in Poznan (Poland) in 1999, this time as a separate meeting. It was attended by delegates from 9 countries. The 4th Meeting in Kaunas returned to the tradition and preceded closely the 7th Central European Congress of Coloproctology and Viscerosynthesis.

The aim of these meetings is to bring together ostomates from countries which have similar past and which face similar problems in instituting the modern system of care of patients with a stoma. The main contribution consists in mutual discussions, which could help the countries where the care of ostomates is still on a low level or, in some case, is non-existent.

REPORT OF THE MEETING

The 4th Meeting was organised by the Lithuanian Stoma Patients Association. It was fully sponsored by the firms Coloplast and ConvaTec.

Delegates from the following countries were present: Belarus, Croatia, Czech Republic, Latvia, Lithuania, Poland, Russia (Moscow), Slovakia and Ukraine. EOA and IOA were represented by the Presidents.

Country reports

Belarus (BELAS)

(reported by Lyudmila Chernyak)

- The association was founded in 1993; it was managed originally by a coloproctologist, an ostomate was elected President in 1998.
- The first rehabilitation centre established in Minsk was managed by one physician (surgeon) and one stoma therapist.
- Now 7 rehabilitation centres cover the whole country taking care of more than 4000 ostomates.

- In 1994 a decree was issued on charge-free availability of stoma appliances. Belarus thus became the first post-Soviet country in which the Government changed the legislation to ensure the needs of ostomates.
- Only ConvaTec products are available. The association serves as distributor of the appliances. Therefore all ostomates must be members of the association.
- Problems with the access of ostomates to the appliances persist, since the Government has not enough funds available. Ostomates receive 1 plate and 1 pouch per week. Patients living outside the centres often do not receive any appliances and must use home-made substitutes.

Croatia (CRO-ILCO)

(reported by Milan Mucic)

- There are 4025 ostomates registered in Croatia. Local clubs are associated in a national organisation CRO-ILCO. Its activity was interrupted in 1999 and reassumed in 2001.
- The association organises lectures on the stoma care and publishes a journal *Informator* with actual information. Up to now 12 issues appeared.
- The limit of appliances is 10 flanges and 20 pouches per month. The majority of ostomates use the products of ConvaTec, about 10% of the marked is covered by Coloplast. At present the appliances are reimbursed by the insurance company.
- A reform of the health service is under preparation. It is proposed that a part of the appliance limit should be covered by the patient.

Czech Republic (Czech ILCO)

(reported by Oldrich Capka)

- Czech ILCO was founded in 1993 as an national association of already existing regional clubs of ostomates. At present it includes 13 clubs. Four other clubs exist in the country, which are not members of Czech ILCO.
- The association negotiates with the Ministry of Health and insurance companies the limits of appliances, organises rehabilitation courses (usually one one-week course and two weekend courses) for all ostomates (financed partly by the Ministry of Health on the basis of specified projects) and conferences for ostomates.
- The main task of Czech ILCO is to improve the co-operation with physicians and with its state authorities.
- Four manufacturers (ConvaTec, Coloplast, B|Braun and Dansac) supply the appliances in the Czech Republic. Reasonable limit is fully reimbursed by insurance companies. If necessary the limit may be increased on the recommendation of the control physician. The appliances are available in most pharmacies, specialised distribution centres. All manufacturers organise a mail delivery service.

Latvia (ILCO-LATVIA)

(reported by Nina Panteleeva)

- In 1996 a central stoma cabinet was established Riga. A register was prepared, which includes all ostomates. At present 3399 ostomates are registered. The number of oncological diseases leading to stoma formation. In 2001 577 patients were operated, whereas the number was only 183 in 1996. The surgeries are carried out in three hospitals, in which consultation cabinets are working. Telephone consultations for ostomates are free of charge.

- After operation the patient is visited by a stoma therapist from the central cabinet, who teaches him how to use the appliances and take care of the stoma. This nurse secures the prescription and delivery of stoma appliances in the whole Latvia. No limits exist, each ostomate receives everything free of charge. However, the nurse must optimise the distribution of appliances, since the funds available are fixed by the state budget.
- The pre-operation and postoperation care is not sufficient. Therefore new regional stoma cabinets are being organised.
- The Latvian ostomate organisation has about 400 members. It issues an information bulletin for ostomates.

Lithuania (LiSA)

(reported by Zilvinas Saladzinskas and Juozas Bulota)

- There are about 2000 ostomates in Lithuania now, every year 500 new stomas are formed. The majority of operations are carried out because of malignant disease. One third of surgeries is made in University hospitals, two thirds in district hospitals. Skin problems are the major complication.
- Immediately after the surgery the patients spend 3-4 weeks in a rehabilitation centre, where they learn how to use the appliances and recover. Consultation with a psychologist is also possible.
- The limit of appliances (10 flanges and 20 pouches per month) is covered by the State Insurance Company. The appliances are prescribed for one month and are available in pharmacies.
- The national organisation - Lithuanian Stoma Patients Association (LiSA) was founded in 1996. Now it has about 250 active members.

Poland (POL-ILKO)

(reported by Anna Hebdowska)

- POL-ILKO was founded in 1987 in co-operation with physicians. It consists of 19 Regional Departments now. The main activity is the assistance to the ostomates. In particular this concerns the access to the appliances. Organisational changes in the Polish Health Service and creation of a new health insurance system required intensive negotiation of the POL-ILKO representatives and state authorities.

There are about 17 000 ostomates in Poland, only 1000 of them are members of the Association. POL-ILKO closely co-operates with

- physicians and stoma therapists. It organises training of volunteers for visitor service, which is widely used.
- POL-ILKO publishes a newsletter *POL-ILKO News* and a periodical *Stomik*. It organises regular regional meetings of ostomates and once a year the General Assembly.

Russia - Moscow (ASTOM)

(reported by Aleksander Gordeev)

- The association was founded in 1993 and is active on the territory of the city of Moscow, which has status of a republic in the Russian Federation. It has about 5000 members, however, not all ostomates living in Moscow are registered.
- The association was formed by ostomate volunteers under conditions of complete absence of health and social rehabilitation system as well as inaccessibility of modern appliances. Now the association receives support from the Moscow City Health Department.

- The funds are used for purchasing stoma appliances, which are distributed free of charge to the association members, and for running consultation centres for ostomates, including a specialised children centre.
- A database Stoma Patients Register was created, which contains medical and social information about the patients. It is also exploited for regulation of the distribution of stoma appliances.
- In Moscow about 1500 stoma surgeries are carried out in one year. The majority of ostomates (76.7%) are more than 60 years old. Ostomates can receive information from an information brochure, a library or a videotheke. They can consult their problems with a psychologist. The centres also help ostomates to solve difficult social situations and help them to find a job.
- The association regularly organises seminars for ostomates, in which lectures are given by coloproctologists, stoma therapists and psychologists. In the last two years the association provides its members with free two-week rehabilitation courses.
- The system of medical and social care of ostomates introduced by ASTOM serves as a model for other regions of Russia, in the towns of Krasnodar, Perm and Orenburg. ASTOM also assisted in the creation of ostomate organisation in the city of Odessa in Ukraine.

Slovak Republic (SLOVILCO)

(reported by Helena Pindrochova)

- The association was founded in November 1991. It has 1500 members (out of about 12 000 Slovak ostomates), which are organised in 29 local clubs
- SLOVILCO co-operates with state authorities, constituted a Council of Specialists, the members of which are physicians and stoma therapists and is represented in the State Committee for Disabled Citizens.
- The association is run by volunteers, its activities are financed by the Ministry of Social Affairs and Family and by sponsor gifts. A financial help is obtained from the Ministry of Health for special projects.
- The association organises regularly recondition courses and other social and cultural actions. Every two years it convenes Slovak Ostomate Days. Publishes a journal *SLOVILCO*.
- In this year a two-week course was organised for instructing volunteers for the visiting service.
- Stoma appliances in sufficient limits are fully reimbursed by the health insurance. Products of four manufacturers (ConvaTec, Coloplast, B|Braun and Dansac) are on the market. The appliances are available in pharmacies, consultation centres or can be delivered free of charge by delivery service.

Ukraine (ILCO Kiev)

(reported by Anatoly Sinozhinsky)

- There are about 32 000 ostomates in Ukraine. Due to the Chernobyl disaster the proportion of young ostomates increases. No health insurance or social care exist. Stoma appliances must be paid by the patients and are thus practically inaccessible. The state does not provide any support to disabled citizens.
- In the years 1996 - 1999 a limited amount of appliances was delivered by Deutsche ILCO as humanitarian help. In 1997 an ostomate organisation was formed in the capital Kiev in order to ensure the distribution of these appliances. At present three local organisations exist in Ukraine - in Kiev, Lvov and Odessa. Since 2000 the German help has been directed to the Lvov organisation.

- These three organisations started with preparations to create the national association, but the process is complicated by bureaucratic obstacles and lack of finances. They plan to co-operate with other organisations of invalids in preparing a bill on social rehabilitation of patients.
- There exist stoma consultation centres in Kiev and Lvov, in Odessa a centre is being prepared. In other regions ostomates are without any professional help.

Overview of reimbursed limits of appliances per month

Country	Limit per month		Remark
	flanges	pouches	
Belarus	4	4	limit per week (1 + 1) only ConvaTec appliances available
Croatia	10	20	financial participation of ostomates is under consideration manufacturers
Czech Republic	10	60	4 manufacturers possible increase of the limits if approved by the insurance company reasonable limits for other material
Latvia	none	none	rehabilitation after the surgery
Lithuania	10	20	central register of ostomates central distribution of appliances
Poland	6	35	financial limits per month: colostomates - 72 EUR ileostomates - 85 EUR urostomates - 120 EUR
Russia (ASTOM - Moscow)	5	10	only for citizens of Moscow only ConvaTec appliances available
Slovakia	10	60 90 ileo	4 manufacturers possible increase of the limits if approved by the insurance company reasonable limits for other material
Ukraine	0	0	the only supply of appliances is from German humanitarian help

Summary

From the reports of delegates it follows that sufficient supply of stoma appliances still remains the main problem in most countries. The role of national ostomate organisation in negotiations with proper state authorities is irreplaceable. The ostomates should require that legislative measures be introduced which would guarantee adequate medical and social care for disabled patients.