



EUROPEAN OSTOMY ASSOCIATION

The European Ostomy Associations Coordination Committee's report to the 12. EOA Congress in Brno in The Czech Republic in September 2008.

EOA now has 42 associations in 35 countries in Europe, North Africa and The Middle East. Of those are 33 full members, nine are associate members. There are two associations in Italy, Portugal, Serbia, Belgium, Ukraine and Russia.

The Coordination Committee

After the EOA Congress in Porto, Portugal, in 2004 the EOA-Coordination Committee (CC) consisted of Arne Holte, from Norway (president), Ria Smeijers from the Netherlands (vice president/treasurer) and Efim Krasner from Ukraine (member and responsible for the EOA Newsletter). Associate member was Rita Silanos from Italy. Maria Hass from Germany was attached to the CC as responsible for the EOA directory. She has also voluntarily taken care of sending out info from the president. Also Trixi Schroter from Germany was attached to the CC as part responsible for the EOA Newsletter.

Since then the CC has lost two valuable persons from cancer. First died Efim Krasner in 2005, and in late autumn 2006 Rita Silanos died. The CC is sorry to have lost two very dedicated persons both eager and willing to do as much as possible for ostomates in Europe. The CC with great help from some European Associations was able to provide Mr Krasner with a laptop giving him the opportunity to go on with his good work even when he was hospitalized.

Since the sad death of Efim Krasner, Kes Klare from The Netherlands has been attached to the CC working with the Newsletter. Since the blog page on the IOA website has been introduced in 2007, there have not been distributed any more EOA newsletters, but due to Kes Klare's great passion for ostomates, he has set up a new website www.ostomyeurope.org and he also has taken on the position/job as EOA's webmaster. On this website news from EOA can be read. There will be contact information, and hopefully also information on every association in EOA on the website. The CC is very thankful to Kes Klare for taking on this great and valuable job. Kes Klare will have a stand in Brno showing the website and urging more countries to give their contribution in order to have info from every association in EOA on the website

Efim Krasner was substituted by Alexander Gordeev from Moskow. For EOA it is important to have a Russian speaking person in the CC. The CC has lost contact with Alexander Gordeev which has made contact with the Russian speaking part of EOA more difficult. Obviously Alexander Gordeev has left the Russian organization.

Rita Silanos had a passion for ostomates in Spain, Greece (which she visited on behalf of EOA) and several North African countries. She managed to unite several associations for ostomates in Spain into one organization, and just her illness stopped her from continuing her work in Greece and North Africa. Due to illness has also Trixi Schroter reported that she is not able to go on with her engagement in EOA. So far has not Rita Silanos and Trixi Schroter been substituted.

Arrangements and meetings

The Twinning Conference in Lithuania was the greatest event during the last four years. Delegates from Italy, Russia (Moscow and St. Petersburg), Great Britain, Sweden, Latvia, Denmark, Lithuania, Norway, Canada, Czech Republic, Germany and Ukraine met to discuss how to help countries with small resources – and also to organize the intention with relief work. A report on this work and the outcome from the conference is available by E-mail.

The CC has had four meetings – two in Frankfurt, one in Vilnius and one in Brno - since 2004.

The economy has prevented members of the CC to do a lot of travels. The president has attended The Dutch Ostomy organization's 40 years anniversary in Ede in The Netherlands in April 2006. The president has also attended FAIS Italy's great World Ostomy Day (WOD) arrangement in Montesilvano in October and also FAIS' 5-year anniversary this year. The WOD arrangement was really an example to follow for others. FAIS had managed to combine a meeting with 400 ET-nurses and their own WOD arrangement – also with 400 participants. Present were all the industry and among others a senator from Rome. Arne Holte was so lucky to be able to address that great 800 people audience.

World Ostomy Day 2006

Several other European associations had WOD arrangements. Some have reported their activities, many have probably not. Just to mention the presidents own country, all the 22 local chapters had some sort of arrangements. The CC is familiar with the ideas and concerns written by the 2006 coordinator, Barry Maughan – and I am sure that the new CC will follow up in order to make the next WOD even better.

World Ostomy Day 2009

The CC encourages all EOA member organizations to take part in the WOD taking place the first weekend in October 2009. You will receive more info in the month to come, but mainly it is up to your organization to decide how you will use this important day. The main issue will be to make ostomy and problems attached to having an ostomy known to the public. Both Hollister and Coloplast will arrange competitions attached to WOD. Probably will also Convatec take part in some way. The international coordinator for WOD is Peter McQueen from

Invitations

There have been some other invitations during the last year. The first was to IA's meeting in Newcastle, another was to the new Ukrainian organization's meeting. Due to lack of funding, neither the president nor the treasurer was able to accept the invitation. Apologies were sent and accepted. It was applied to IOA to get 300 euros to be able to send the IOA president, Vladimir Kleinwächter, to the meeting in Ukraine. Against two votes the apply was rejected. I am very sorry that neither EOA nor IOA were present as Ukraine is a country in great need – and the nationwide organization is very new.

In June last year the president attended the Nordic meeting on the Faroe Islands. The travel was sponsored by COPA, Denmark and NORILCO, Norway.

National activities

There is great activity within the different associations in Europe. This will of course vary from country to country – and from time to time. To have a day to day view on what is going in all the 42 associations is impossible. Also the communication may be a problem. However with Maria Hass and Deutsche ILCO's help communication via e-mail/internet has been reasonable good. Last year all associations once again have got the charter and being asked to

translate it and put it on their homepage. Unfortunately there are still a couple of associations that do not have internet.

Another problem – and a great one – will of course be the language. There is no doubt about translation from English is available everywhere, but even so the CC is aware of the problems language may cause. It is said that there are about 100 languages just in Russia...

The CC had planned to send out a simple to understand survey on the conditions for ostomates in Europe. As IOA were considering doing another World Ostomy Report, we left our suggestions to Brenda Flanagan who has made our questions a part of the IOA survey. Many associations in the world answered the questions. Such a survey is valuable to get a view on the conditions for ostomates all over the world.

There are still countries in Europe that do not have an organization for ostomates. There have been inquiries from Armenia and Kosovo to help start organizations there. Alexander Gordeev from the CC was set up to work with Armenia, and we lost contact with Kosovo after we asked for more info, and we have lost contact with Alexander Gordeev. In Greece and Turkey there are associations, but those are not members of IOA/EOA. The CC has started the work to bring them into IOA/EOA.

World Council of Enterostomal Therapists (WCET)

EOA will increase the cooperation with WCET in the future. Both organizations look forward to cooperate on twinning projects. During the IOA congress in Puerto Rico in 2007 the EOA president had a meeting with Susan Stelton from WCET where the conclusions were closer contact and also mutual information whenever a new country were to be visited/contacted in order to start projects. This conclusion was repeated during a meeting in Ljubliana in June this year where the IOA CC met with WCET president Elisabeth English and other representatives from WCET. Among those was Mary Quigley from Ireland – who is here at the congress in Brno. Mary will take part in the twinning conference to-morrow. The new EOA-CC will have to appoint a special twinning contact person on a meeting this Sunday.

The Brno congress and economy

There has been a lot of work arranging this EOA congress in Brno. The planning started already a year ago with a meeting in Brno. The local committee had already engaged TA Service, a well known company in Brno with a lot of experience in such matters. A contract has been set up. The cooperation with the local committee and TA service has been very good, but sitting up in Norway trying to get an overall view has from time to time been somewhat difficult.

The economy has also been rather complicated as the major companies of ostomy appliances did not contribute in the way we had reason to believe. The president flew to Copenhagen and met representatives from Coloplast and Dansac in good faith of getting the applied amount of 11000 euros from each. Hollister and ConvaTec were contacted by phone and e-mail. The negotiations seemed to turn out very well, but no response came within the accepted deadline. After a number of reminders there were negative answers from Dansac/Hollister and Coloplast, but ConcaTec gave the 11000 euros we asked for. Due to this situation, the CC agreed to use up to 12000 euros of our savings.

There has been, however, a lot of goodwill from local – and also some minor companies. The CC is very grateful to Isilco, Iceland, IA – Great Britain, COPA – Denmark, NORILCO – Norway and The Dutch Ostomy Association – The Netherlands who all contributed. Ultimately also Dansac in Denmark and Hollister International has given smaller amounts. Three Norwegian companies are contributing in order to bring one person from a new possible member association to the congress, and the CC will use some of the received money for bringing

people from countries and associations to the congress. There are also some associations present at the congress that have been paid for by twin partners.

Thanks to those contributions the CC has a more positive impression concerning the congress economy than we had just some weeks ago. The CC is very thankful for all those contributions.

As this report is written in the end of August it is not clear whether the congress will give a loss or not. The contract between Czech ILCO and EOA states that both surplus and loss will be 50% on each association.

The International Ostomy Association (IOA)

Arne Holte, as president of EOA, is automatically a member of the IOA Executive Council (EC). There have been just a few meetings the last period. Since the IOA Congress in Puerto Rico in August 2007 there has been only one meeting. Due to joint effort from the main producers of ostomy appliances/equipment, the EC was able to meet in Ljubljana in June this year. The president has to point out that the work in the EC has been difficult the last year. It seems that Europe in some way is being squeezed out. In the president's opinion the rest of the EC do not seem to pay any attention to the problems the great number of associations and also languages in Europe cause. It is also a problem that the only other European in the EC, Vladimir Kleinwächter, has resigned.

The future

As you will know there will be discussion on the future of EOA at a workshop at the congress in Brno. There we will have to discuss various solutions. One will be to divide Europe into two or three regions, another may be to have subgroups – a third option may be to remove EOA from IOA. The CC invites you all to take part in exiting discussions.

Independent of the future structure of EOA there will be a lot of vital tasks for the EOA coordination committee in the years to come. One major question will be to decide what is most vital and important: to create vivid organizations for ostomates, led by ostomates – or travel to countries with poor economy to have seminars and courses for doctors and nurses. Along with such arrangements it is possible to teach the ostomates to run a visiting service. Today's CC sees it most important to build up organizations that are run by ostomates, organizations that work according to the "Charter of ostomates rights".

Teaching is also very vital, so is it to have a friend – someone who cares. That is the reason why this CC encourages to start twinning arrangements. As you know there will be a twinning workshop to-morrow. We hope for good outcomes from this.

One important task for the CC – or in fact for all of us – will be to become a family, the great EOA ostomy family!

The Coordinating Committee of the European Ostomy Association, in August 2008

Arne Holte, president

Ria Smeijers, vice president and treasurer