

## **Danish Ostomy Association COPA**

The Ostomy Association COPA is the world's oldest patient association for persons with ostomy. This year on Saturday the 27<sup>th</sup> August we celebrate its 60th anniversary with a major event in Vejle, Denmark.

The Ostomy Association COPA has approximately 3,500 members, and the number has been stable over the recent years. But it is desirable to have more members, as there in Denmark are approximately 10,000 to 12,000 persons with an ostomy.

The Executive Council consists of 20 persons: national chairman, local chairmen of 16 local associations and 3 interest groups. The Local Associations covering geographical areas equivalent to the former counties, the interest groups are as follows: Parent Group, Youth Group and FAP (Familiar Adenomatous Polyposis).

In addition there are 2 colitis/crohn groups (east and west) and 2 urostomy groups (east and west).

The Executive Council meet two times a year: in April to the Ordinary Meeting of the Central Board and in November to the Activity and Budget meeting for the following year.

The daily management is handled by the Bureau, consisting of the national chairman and 4 local presidents (one is selected as Deputy National President), and an alternate for the bureau.

The association has a secretariat with a full time secretariat director.

A member magazine is published 6 times a year, and together with the last magazine of the year a pocketbook with calendar for the following year is attached.

Subscription for members per year is 225 DKK. and for pensioners and support members 125 DKK.

All local associations and interest groups will have an annual operating grant of DKK 8,000.

Local associations will further receive 65 DKK per member in their local chapter. Local Associations are responsible for their own events and their annual general meeting.

The interest groups must hold annual regional activities.

The National Association holds every year the following events: Summer holidays, Weekend and weekend course for our volunteer counselors.

The Association revenue of approximately 2,700,000 DKK per annum (2010) is derived from contributions from Danish National Gaming (Tips / Lotto), membership fees, advertisements in the member magazine, fees from participants in events and an annual grant from KB (the Danish Cancer Society) of 160,000 DKK.

The association is a member of DH (Danish Disability Organization), EOA ,IOA and NOA.

There is an agreement with KB and FS (Professional Society for Nurses in stoma care).

The Ostomy Association COPA has previously helped in Lithuania with the start of a patient association for their ostomy patients. The help has been paying for accommodation and travel expenses for doctors and nurses who came to visit Denmark in order to learn about surgical techniques and ostomy care, participation in congresses of ostomy associations, the creation of a union office and for information etc. Our help to Lithuania ended in 2006.

Since then we have helped to send ostomy products and aids to Odessa in Ukraine. Persons with ostomy in Ukraine do not get subsidies for the purchase of ostomy aids. Therefore, it is a huge financial burden for the individual to pay these expenses by himself.

We have chosen only to help patients from Hospital No. 10 in Odessa. The reason for this is that both doctors and nurses at this hospital provides information and assistance to get on with life after a stoma construction. On the other hospitals in Odessa and many other places in Ukraine, patients should take care of themselves after surgery.

The help in sending ostomy equipment from Denmark to Ukraine should however only be a temporary emergency measure for a while (probably a few more years). At some future time it will hopefully be possible for persons with ostomy in Ukraine to be reimbursed for their expenses for ostomy aids.

The Icelandic Ostomy Association is helping our project in Ukraine by sending surplus ostomy aids to Odessa. The Ostomy Association COPA has at several occasions assisted the ostomy association in Odessa in paying for their participation in congresses for ostomy associations in Europe.

Here in Denmark we are however fortunate despite large savings in health care. We still get our ostomy aids paid for by public funds.

But there is an unfortunate and undesirable development, with the closure of more and more stoma out-patient clinics. Many local hospitals are being closed and therefore the stoma clinics are also closed with the effect, that the time for transportation is extended for consulting the stoma nurse.

Previously there have been many distributors of ostomy aids. According the EU law it is mandatory to invite for bids for larger contracts, and we must face the fact that there are now only a handful of dealers left in Denmark.

An offer regarding Patient Schools for Ostomy patients is currently only possible in the counties of Hvidovre, Køge and soon in Herlev.

Ostomy nurses and the Ostomy Association COPA should like this offer to be available in more places in Denmark, but with savings in health care it may be problematic to acquire funds. We must hope for better economic times - in the future.

This was a little bit about the Danish Ostomy Association COPA.

Greetings to you all with the best wishes for a good summer.

Henning Granslev.  
National Chairman COPA.