

## Country Report to the European Ostomy Association EOA 2017



### Organization:

**Deutsche ILCO e.V.**

(German Ostomy and Colorectal Cancer Association)

Thomas-Mann-Str. 40  
53111 Bonn, Germany

**Tel.** +49 228 338894-50

**Fax** +49 228 338894-75

**E-Mail:** [info@ilco.de](mailto:info@ilco.de)

**Internet:** [www.ilco.de](http://www.ilco.de)

### Number of members in total (2017/01/01): 7.235 persons

- people with all types of ostomies (because of different diseases or other reasons) and people with colorectal cancer with or without an ostomy: in total **5.941** members

- relatives: **480**

- supporting members: **814**

**National Board:** max. 8 persons (ostomates or people with colorectal cancer or relatives). All are volunteers. Number of persons in the actual board: 7

**Employees** (only in the national office): 1 full time, 7 part time

**Estimated number of ostomates** in Germany: about 150.000 with an ostomy (no distinction between temporary or final ostomies). Unfortunately there exists no validated database.

**Financing** of the Deutsche ILCO: membership fee (36 EUR/year), German Cancer Organisation "Deutsche Krebshilfe", Public Health Insurances and – from time to time – (mostly smaller) donations. No support or sponsoring by companies which are active in the 'health market' (rules of independence)

**Appliance situation:** A lot of different products of many different companies are available. Problems: **(1)** poor independent consultation possible, consultations are mainly given by those who are sellers or distributors of appliances, **(2)** There is no general definition of advisory service – and there is no extra payment from the health insurances for advice and support which is more extensively (f.e. when stoma-problems occur), **(3)** The further education and the profession of an "enterostomatherapist" is not officially acknowledged – everybody is allowed to name himself ET. Most of the ostomates don't know which kind of knowledge "their" ET has. **(4)** Last year it was the first time that a public (!) health insurance company has made a call for bids for the ostomy care of their insured persons. An ostomate can only choose between 3 suppliers now (those who have won the call for bids). If these winners will reduce the amounts of appliances – we watch that carefully. This new situation brought and that brings a feeling of uncertainty to a lot of ostomates – not only to those who are insured by this health insurance but also to others. They are afraid that their insurance will follow the "example".

**Conclusion: appliance situation is still good but perhaps endangered**

### Type of reimbursement:

Doctors prescribe the products. The appliances are paid by the Health Insurances except 10% → ostomates have to pay these 10% by themselves but at the most 10 EUR per month (120 EUR per year).

If you need more than a - by the health insurances – defined quantity of appliances per month (average consumption) the necessity must be checked and justified by a doctor (and/or a stoma nurse). Otherwise the ostomate has to pay the quantity over the average consumption by himself. Health insurances are allowed to check if the explanations of stoma nurses and doctors are correct.

### Activities of Deutsche ILCO:

- 285 local chapters organized in 87 regions
- 8 associations on land level (coordination of visiting service, information, exchange of experiences, organisation of chapters and of regional events)
- about 800 volunteers in all kinds of tasks
- 14.000 visited people every year in hospitals, in rehabilitation clinics and at home (>90% of them were ostomates)

### Activities on the national level:

- National Delegates Meetings every 3 years (last June 2017) -> responsible for the election of the national board, for changes of the association's constitutions, for decisions touching the general direction of the association
- Issue of own brochures (see below), leaflets and other information, Website
- Journal "ILCO PRAXIS" published 4 times a year
- Seminars/trainings/meetings for the volunteers in different tasks (f.e. chapter leaders, visiting service in hospitals and rehabilitation centres, treasurers, board members)
- Public information meetings
- National conferences (public) like National Urostomy Conference, "ILCO-Tage" (both three-annual) , ILCO ± 35 (annual meeting for younger people)
- Advocacy work in different bodies of experts (f.e. social and health politics, health care system, treatment guidelines and patient guidelines, National Cancer Plan) – depending on the topic the work is done in cooperation with other national selfhelp association.
- Cooperation with Colorectal Cancer Centers
- Cooperation with other selfhelp associations – f.e. DCCV (Inflammatory Bowel Disease Association) and different cancer associations: Joint actions or joint advocacy work.

### Special activities and successes from 2014-2017:

- "Top act" in 2014 had been a **multidisciplinary congress** held in Freiburg (near the Swiss border) which was organised by Deutsche ILCO, by the German branch of ECET and by the university hospital of Freiburg. Ostomates, stomatherapists, psychologists and doctors followed the reports and participated in the discussions.
- In June 2015 a **National Urostomy Day** was organised with reports and discussions. At the same time the relatives got the possibility to discuss their problems in a separate group. The relatives liked this special offer and it was decided to develop it.
- **Cooperation with more than 250 Colorectal Cancer Centers:** Cooperation is fixed by a written agreement and signed by both, centers and Deutsche ILCO. The agreement fixes defines offers of Deutsche to the patients with colon cancer and/or with an ostomy as well as the support of these offers by the hospital/center. Deutsche ILCO offers f.e. visiting service, information about the Deutsche ILCO and the life with an ostomy/with colorectal cancer, cooperation in congresses of the centers. Every volunteer bind himself to strict data protection.
- **World Ostomy Day 2015: "Many stories, one voice"**  
There were two activities:



1. Deutsche ILCO had a postcard campaign. At the front, the postcard shows information and terms concerning the world ostomy day, such as the motto, logos, the QR code and link to the website. At the back, the motto had been addressed again: ostomates and their relatives could write, what the Deutsche ILCO should raise its voice for, for what it should campaign. The postcard had been distributed all over Germany: directly to ostomates, but also at events, in hospitals and to health insurances, pharmacies, medical stores, cancer counselling centres, self-help contact points, city councils etc. The feedback we received was somewhat astonishing: Deutsche ILCO should help that ostomates have no longer to face restrictions in using (public) swimming baths because of "hygienic reasons". We followed this wish and need of our members: We could publish several statements from doctors and stomatherapists in our magazine – and we got a statement from the National hygienic institute that there is no hygienic reason to keep away ostomates from swimming baths. These documents were very helpful.

2. As even today for many people the fate of obtaining an an ostomy is associated with dread, anxiety and shame. Deutsche ILCO has literally given ostomates a voice to set something against that taboo: On the website [www.ilco.de/stoma/erfahrungsberichte/](http://www.ilco.de/stoma/erfahrungsberichte/) ostomates and their relatives speak about their lives and experiences. These people are trustworthy witnesses for the joy of living in spite of and with an ostomy – and they thus oppose ignorance, prejudices and the taboo “ostomy”. 14 short life stories can be listened as well as they can be read.

- **National Congress held in 2016 in Hamburg**



The motto of the congress was “It’s nothing you can really pay for – The value of selfhelp associations“ („Was man für Geld nicht kaufen kann – Vom Stellenwert der Selbsthilfe“). More than 200 participants - most of them active members like chapter leaders or volunteers in the visiting service – came to listen, to discuss and to have fun. Reports concerning the main topic gave interesting information and they were a good motivation for all volunteers to go ahead with their work. A report which announced the use and the risks of social

media had been very welcomed by the participants. This morning was followed by an afternoon with several workshops, f.e. for young ostomates, for relatives, for people with an ostomy after inflammatory bowel diseases, for people who had their ostomy reversed, for those who are interested to work with social media and for those who like to learn some easy sporty exercises.

The whole day all participants could also inform themselves at an exhibition where they could also meet several appliance companies with their lines of products.

The organized evenings allowed to meet old friends from other ILCO-regions in Germany and to make new friends. All participants had a wonderful time – and a lot of participants took the chance to dance for hours! The congress ended on Sunday morning with a boat trip around the harbor.

- **National conferences:** A “House of Delegates” took place in **July 2014 and in June 2017:** The three annual House of Delegates includes discussions on the development of the association, possible changes of the constitution and the elections of the new national board.
- **Logo of Deutsche ILCO:** After 20 years the wellknown logo had been slightly changed. It was a very careful change because the logo should be still identified at once as Deutsche ILCO – but should also give an expression which is a little bit more dynamic.
- **New Media:**

- a facebook-site since 2014 <https://www.facebook.com/DeutscheILCO.de/>

- a facebook group only for young ostomates since 2015



the volunteers!

- two relaunches of the website [www.ilco.de](http://www.ilco.de) – the last had been in spring 2017

- ad-free web-forum since June 2016 [www.ilco.de/forum](http://www.ilco.de/forum)

- run by 8 volunteers (2 every day) who welcome new forum-members and who look whether the rules are followed. It is a half- publicly forum: some topics need a registration to be readed and you can only write something if you are registered. It is very successful with now more than 520 registered members and a lot of observers. But it affords a lot of time and idealism from

### Brochures available:

- Colostomy / Ileostomy – a guideline
- Urostomy – a guideline
- Irrigation – a method for colostomates to clean the colon
- Nutrition after ostomy and colon surgeries
- Lust for live – experiences of ostomates
- Colon cancer – living with the impacts
- Ostomy Dictionary: 103 ostomy terms in 21 languages\*)
- Check out! – A glossery of medical terms

... and other leaflets and advice sheets

\*) We are proud that the little **ostomy dictionary** which had been started by an international group of young ostomates in the late 80<sup>th</sup> of the last century has grown to a real booklet. The actual edition encloses now **20 european languages and the Arabic language**. With the support of ostomy associations from other countries we could complete the dictionary bit by bit. **Thank you to all who helped us with corrections or new translations.**

The dictionary is not only used by travellers but also by the visiting service in hospitals, by surgeons, nurses and socialworkers and by people who work in the consultation of refugees.

### Main tasks and challenges from 2017 to 2020:

- To oppose all tempts to worsen the good situation for ostomates (no. of appliances, costs)
- To stop the trend towards the decrease in the number of members, attracting of new members
- To gain more financial independence which means: To recover more independence of the current grant donors – and at the same time to remain independent of funding by enterprises like pharmaceutical industry or appliance companies
- To develop and to publish a new brochure for those who will have their ostomies reversed

03/10/2017

Signed: Maria Hass

Deutsche ILCO e.V.