

Country report 2010

Dutch Ostomy Association

2010 was a memorable year. A lot happened in the political field and there was much work to be done fighting for the rights of ostomates. We had an annual 'theme' for the first time: sport. This proved to be successful and gave us positive feedback from our members.

In the Netherlands there are about 28000 ostomates of whom 7919 are members of our association. 15.7% are female and 48.3% male. 71% is older than 60. 50% has a colostomy, 28% an ileostomy, 16% a urostomy and 6% has a pouch or otherwise. 67% has an ostomy due to cancer, 23% as a result of Crohn's disease or ulcerative colitis and 10% otherwise.

Activities during the year:

- The 8 regions organized 413 different activities in all in 2010, consisting of theme days, coffee mornings, lectures and visits or phone calls from our visitor's service.
- 1400 visitors attended our 3 national meetings and the main theme was 'sport'.
- Our online forum had 428 reactions and our helpdesk had 2378 phone calls varying from requests for documentation to giving advice.
- The young ostomate group organized 2 meetings in 2010.
- The website has been improved and updated in 2010 and the forum is easier to use. As a result there has been an increase in visitors to the site.
- There were 2 digital newsletters in 2010, which enabled us to react to the news of the day and to actual questions within the organization.
- We have been working on 2 new leaflets – one for our visitors service and a general folder – both should be ready for publishing at the beginning of 2011.
- We are also working on a comic book for children in the age group 10 to 16 years old. This should also be ready early in 2011.

The role of the Dutch Ostomy Association as 3rd party alongside health insurance companies and health care workers has increased in 2010. We have participated in various committees and projects:

1. The project: 'Visiting Healthcare organizations' was set up to clarify the quality of ostomy care in The Netherlands.
2. The Platform for Ostomy Care and appliances, which consists of 4 organizations in all. Our aim is to provide a well-documented review of developments in ostomy care and appliances that can be adapted whenever new developments arise.
3. We also took part in writing a patients guide to bowel cancer, together with 3 other patients organizations. It reviews the quality of care in Dutch hospitals, for patients with bowel cancer and is a guideline when choosing which hospital to go to for treatment. The target is to further develop this guide between 2011-2012 based on our quality criteria.

- New legislation for the chronically ill has resulted in ostomates not receiving full compensation for ostomy appliances. The Dutch Ostomy Association has protested against this, but unfortunately without result as of yet.
- In 2010 we started to update our quality criteria and hope to finish this project in 2011.
- The NS (Dutch Railway) has decided to do away with toilets in slow trains. The Dutch Ostomy Association, together with other organizations, protested against this, with success. The decision to remove toilets has been withdrawn.
- Two years ago we launched a Stoma Panel, to enable us to anticipate on questions and the needs of ostomates in The Netherlands. In 2010 we held 2 questionnaires – one about appliances and one about the level of satisfaction of our members towards service supplied by us.
- In 2010 we applied for subsidies for 2 projects and in December we received news that they were both granted. One project is to develop a Patients Guide to Ostomy Care and the other is a combined initiative with 2 other patients organizations, with as aim combining and expanding on patient's expertise and efforts, using social media such as twitter, hyves, facebook etc.
- The Governing Board and Management have seen the need to start developing a new governing model, which will help the organization to fulfill her mission in the future. They have applied for subsidy to develop this further. Consulting our members is of vital importance here in.

The Dutch Ostomy Association has been around for nearly 45 years and there is still a lot of work to do.