



## Cancer Support in 2010

Brussels, April 2011

## **Introduction**

The Cancer Support Group (CSG) has now been in existence for over six years. A report was drawn up in 2007 recording and evaluating the CSG's activities 2004-2007.<sup>1</sup> Further reports provided a follow-up covering 2008 and 2009.<sup>2</sup> The current report describes the activities of the CSG in 2010.

## **Organisation and Members**

The membership of the group is open to all active and former members of staff and their families who have direct experience of cancer either as a patient or as a family member or friend of someone who has had cancer.

The coordination group is responsible on a rota basis for answering telephone calls to the CSG telephone number and for dealing with e-mails sent to the CSG e-mail box. Unfortunately, the number of colleagues available for these tasks diminished during the year due to pressure of work. Some colleagues found that although their hierarchy was largely supportive of the CSG's activities, they were unwilling or unable to allow members of the coordination group free time for CSG activities. A recruitment campaign was launched with the object of increasing the number of colleagues and thus spreading the burden.

Two meetings were held on 25 May and 29 June to discuss the future of Cancer Support attended by about 20 members. These were prepared for by two preparatory meetings.

The Group therefore decided to organise a series of training courses on "Communication en Oncologie" in the attempt to recruit some new members of the Coordination Group. This course – divided into four sessions held between January and March 2011 – was given by Mrs Roser LLOP I FAIG, a qualified psychologist specialized in working with cancer cases at the Bordet Clinic and elsewhere. Mrs LLOP I FAIG kindly provided the first course free of charge. 14 members of staff attended the course and several subsequently joined the Coordination Group. A second edition of the course was held between December 2010 and February 2011 and attended by 8 members of the CSG. Six of these members were sponsored by DG TAXUD.

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<sup>1</sup> Available on the CSG website [www.cancer-support.eu](http://www.cancer-support.eu)

<sup>2</sup> Available on the CSG website [www.cancer-support.eu](http://www.cancer-support.eu)

In 2010 the Coordination Group met eleven times during the lunch break to discuss cases and to plan future activities. A larger annual meeting of all active members was also held on 29 November. At the Annual Meeting Ms Mary Preston stepped down as President of the CSG. Her place was taken by Mr Roy Edwards.

The CSG has some 30 Active members and 60 interested colleagues on its mailing list.

Following its recognition as a self-help group with a status assimilated to that of one of the "cercles de loisirs", the Group receives a grant from COPAS for expenses and a meeting room where the coordination group meets. The meeting room is also used for a number of well-being activities. The Group would like to take this opportunity to thank COPAS for its very valuable support.

Since 2006 the CSG has been a registered a.s.b.l. under Belgian law.

The CSG website ([www.cancer-support.eu](http://www.cancer-support.eu)) which is now on an external host has been regularly updated. A newsletter is now circulated every month to members.

### **The Cancer Support Groups's main tasks:**

From the start the CSG's main task has been to provide emotional support and practical assistance to colleagues or members of their families facing cancer on a one-to-one basis.

Colleagues get in touch by telephone or e-mail or are sometimes referred to the group by the Medical Service, a social welfare assistant or by another colleague. The Group's statistics indicate that it received 82 enquiries in 2010 which led to 55 new cases. It should however be noted that this figure does not accurately reflect the number of colleagues who contacted us since some enquiries are on a personal and private basis and are not usually counted in our statistics.

Some enquiries can be dealt with on the spot but others may mark the start of a process which involves following a "client" for months or even years. Nearly always the colleague needs to talk about his or her problem and a good conversation can often provide the reassurance or advice needed.

People indeed cope with their emotions in different ways, but most of them find it cathartic to openly express how they feel. They are likely to experience a series of emotional stages after the breakdown. They might feel angry, shocked, depressed or frustrated and fearful. It is important to recognise these feelings as normal but try to stay positive as they take the first steps in moving on with their life and cure. They can address their fears and therefore maintain their mental wellbeing.

In 2010, 6 cases required consulting other members, 4 led to contacts with the PMO and in 18 instances the CSG organised appointments with cancer specialists either at the Bordet Clinic or at the University Hospital in Leuven.

4 cases have involved a longer term commitment by CSG members over several years. One example is that of a former colleague (not an official) who could not be treated in her country of residence and has therefore been regularly hosted by a CSG member when returning to Belgium for treatment. This made having the treatment outside her home country financially accessible. Almost two years after being told in her home country that her cancer was untreatable and that she had only months to live, not only is she still alive but the latest scan showed that the tumour had shrunk slightly.

As noted in the previous report colleagues turn to the CSG for help for many different reasons. The degree to which they wish for or need support varies greatly on temperament, family situation and other factors. However, what does seem clear is that having cancer is a life-changing experience and most patients who receive support from family, friends, and a professional such as a psychologist or an organisation such as CSG seem to weather the experience better than those who try to "go it alone".

The CSG's excellent relations with the Commission's social welfare assistants in DG HR C1, and the Commission's Medical Service - Brussels have continued.

Since the introduction of the Commission's Well-Being policy, the CSG has had frequent contacts with the network of well-being coordinators in the DGs and has collaborated with them in organising a number of meetings and activities.

These included:

- ⤴ Weekly well-being relaxation and stretching workshops (lunchtime activity): +/- 60 persons.
- ⤴ Social Assistants from the Medical Service – Brussels used our room to run a series of groups on integrating and socialising in Belgium (lunchtime activity)
- ⤴ 21/01: 'Introduction to Gestalt Therapy' (lunchtime activity): 25 persons.
- ⤴ 25/01 & 8/02: Stress management workshop (2 lunchtime sessions): 6 persons.
- ⤴ 01/03: Presentation of CSG at the "Newcomers' lunch - DG TAXUD": 14 persons + 3 organisers
- ⤴ 31/05-26/07 Workshops on « How to enjoy green tea » (6 Monday lunchtime sessions): 6 x 10 persons.

- ⤴ 3/06 Talk on ' Le secret des centenaires d'OKINAWA : Comment vivre sans maladies, longtemps et mieux ?' par le Dr Dominique Méan <http://domean.net/> (lunchtime activity): about 60 persons.
- ⤴ 7/06 Prsentation 'Nos meilleures recettes avec Jazz Max' et tasting in connection with Bio Week: 15 persons.
- ⤴ 22/10: Launching of the Reiki workshop. (21 individual sances).
- ⤴ 15/11: Workshop 'La pratique des huiles essentielles au quotidien' (lunchtime activity): 20 persons.
- ⤴ 18/11: Lunchtime conference à la DG REGIO: 'Présentation du Cancer Support Group'.
- ⤴ 1/12: Presentation of the film Living Downstream from the book by Sandra Steingraber in the presence of the author [www.livingdownstream.com](http://www.livingdownstream.com) and debate (collaboration Health & Environment Alliance) (lunchtime activity): 37 personnes.

## Ancillary tasks

**Translation of documentation on cancer:** Under the agreement between the CSG and thanks to the support of some translators and former translators, further brochures produced by the University Clinic at Leuven (UZL) have been translated into English and other brochures are in the pipeline.

**Awareness-raising:** On 14 October 2010 the CSG held a fourth successful Cancer Awareness Day in the Guimard building, on the subject "Male Cancers are also a woman's concern". The event took the form of a round table discussion with a number of panellists from the medical, preventive health and political worlds as well as cancer survivors debating and answering questions focusing on:

- ⤴ Men's health issues and the need to follow regular health checks.
- ⤴ The role of women in encouraging men of all ages to take advantage of preventive measures.
- ⤴ Raising awareness of men's health issues, specifically prostate cancer.
- ⤴ Identifying the support role of family, friends and colleagues and the need for communication.

Why was this topic chosen? Simply because the Cancer Support Group had become increasingly aware that whereas most women do seem to have really understood the message about the need for regular health checks, men, whatever their age, have not always got the message. Male cancer sufferers also tend to react differently to the news, by keeping silent and withdrawing from social life, which can considerably diminish their ability to deal with their illness.

The panel was made up as follows:

- ⤴ **Vice-President Šefčovič** who supported us by opening the session.
- ⤴ **Mr Daniel Jacob**, Deputy Director general DG Human Resources and Security representing **Mrs Souka**, the Director-General of Human Resources and Security. Mrs Souka had kindly given her agreement for the event to take place within the scope of the *Commission's Wellbeing Programme* and thus included in Syslog. This made it easier for interested staff to attend.
- ⤴ **Dr Peltier** and **Professor van Velthoven**, leading urologists from the Bordet hospital in Brussels and **Dr Bilbao**, a doctor from the Commission's medical service.
- ⤴ **Mrs Roser Llop**, a psychologist, has experience in rehabilitation and the supportive role of the family.
- ⤴ Two Cancer Charities (**The Belgian "Fondation contre le cancer" and "Movember"**) were also represented. The former by **Dr Didier Vander Steichel**, Medical and Scientific Director, who had responsibility for over twenty years for the charity's "Cancerphone", and **Toby Godman**, Movember's Brussels spokesperson.
- ⤴ A **Commission colleague**, himself a cancer sufferer, and **the widow of a former official** also spoke on their experiences and contributed to the debate.
- ⤴ Christiane Gronau, a professional journalist kindly agreed to be **moderator**.

The audience was also shown a recently taped interview with **Mr Alojz Peterle MEP**, the European Parliament's rapporteur on the Commission's communication on "Action against cancer: European Partnership" and the current **chairman of MAC** (Members Against Cancer).

Contact was established with "Movember", an organisation which was founded in Australia ("Mo" is Australian slang for moustache) and whose members help men affected by prostate cancer. They have a tradition to grow their moustache during the month of November.

### **Contacts with other EU institutions**

Contacts with other EU institutions in Brussels have continued, in particular with the European Parliament through Mr Peterle, MEP and current Chairman of MAC (Members Against Cancer). On 17 November a meeting was held to set up a specific group at the European Parliament. We have also continued to improve contacts with the social welfare assistants and medical staff in the other institutions which should enable us to handle enquiries from colleagues in these other institutions more effectively in the future.

## **Future plans**

**Fund-raising:** The CSG is actively looking for a new project for its fund-raising in 2010-2011. It would like to support cancer care in a different member State over the next two years.

**Awareness-Raising Day 2011:** Given the success of the previous three days, we have already started to organize our 2011 event which will be held once more in October. This year, we shall concentrate on the effect of cancer on the patient's family and close friends. Caring for and supporting someone who is seriously ill is a physically and mentally demanding task and these people often need our support as much as the patients.

## **Final word**

Although we do not have any statistics for the number of cancer cases among EU staff, the figures for the general population indicate that one in five people get cancer before retirement age. This means some thousands of Commission staff get cancer every year. The policy on invalidity has considerably improved in the last years and the aim is now to help cancer patients to come back to work whenever their health makes this possible. All cancer experts are unanimous in recognizing the psychological effects of cancer and that treating these successfully is vital for a good recovery. This requires social and emotional support which is particularly important in the case of patients who may not have any family in Belgium. CSG provides an important additional support to the services provided by the Medical Service – Brussels to active staff and the social welfare assistants in DG HR C1 to retired personnel.

As a self-help group the CSG also fosters the feeling of solidarity among Commission staff which has inevitably declined as the organisation has grown.

2010 demonstrated yet again the usefulness of our work. We have built up a wide network of contacts within the Commission and with clinics in Brussels and these help us to solve many problems which might otherwise cause extra worry for colleagues who already have to cope with a serious disease.

However, recruiting and retaining enough colleagues for the coordination group has continued to be a real challenge in 2010. Members of staff who are active in the CSG do sometimes need some time during working hours to devote to this. Although most Heads of Unit are sympathetic to our work, it does place in particular the members of the coordination group in a difficult position if they have to constantly ask for this time as a sort of "special favour".

We are hoping that in 2011, the year of voluntary organisations, this problem can finally be solved.

