

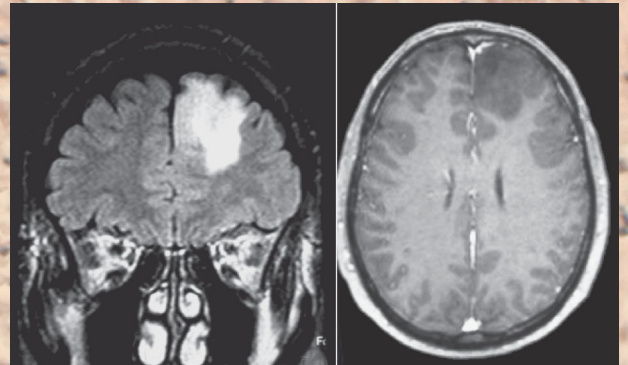
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The Swedish Brain Tumour Study Group in the Framework of a New "Patient in the Focus of Cancer Care" in Sweden

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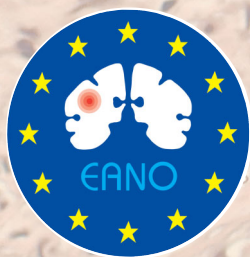
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The Swedish Brain Tumour Study Group in the Framework of a New “Patient in the Focus of Cancer Care” in Sweden

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In Sweden, approximately 57,000 people are diagnosed with a cancer disease and among them are 1,300 new primary brain tumours every year. The number of new patients suffering from brain metastases is estimated annually to be approximately up to 10,000.

The Swedish Brain Tumour Group, a non-profit organisation, was founded in 1993 with 2 main goals – to create public awareness of a neglected patient group in society and to improve health care standards for patients suffering from brain tumours. This national group was supported from the beginning by the national Cancer Foundation and by the departments responsible for the care of brain tumour patients, ie, in Sweden departments of neurosurgery, neurology, and oncology. The departments involved are mainly located at university hospitals but some patients are also given non-surgical treatment at oncology departments outside universities. The National Group holds formal meetings 4 times per year.

■ Science and Research

An important activity has been to promote science and neuro-oncological research. The group has initiated and finalised several important clinical studies, such as the elderly study recently published in *Lancet Oncology* [1]. The whole group, or part of it, has taken part in many national and international clinical studies in different clinical settings. In addition, members of the group have important roles in various molecular and genomic studies of brain tumours, published in highly ranking journals. Neuropathologists and neuroradiologists are also active participants in this neuro-oncological network. In addition, the group closely collaborates with the national association of nurses in neuro-oncology and also neuro-psychologists. Several scientific publications have stemmed from these collaborations.

■ Cancer Registry

Sweden has > 20 national clinical databases related to cancer, including the cancer registry to which all patients diagnosed with cancer have been reported since 1958. The National Quality Registry for primary brain tumours, a subgroup of the Swedish Brain Tumour Study Group, was initiated in 1999 for primary registration and extended to follow-up registration in 2006. The aim was to ensure good treatment for all brain tumour patients with a high international standard and without regional differences. Registration is regionally based. Every year, all data is aggregated on a national level and reported. This registration covers > 90 % of all patients with primary brain tumours although further improvements in the registra-

tion are needed for some regions. The national brain tumour registration covers aspects not included in the legally decided cancer registry, such as treatments, time for management, complications, and follow-up parameters like survival.

■ Patient Advocacy Group

Members of the national group have supported the foundation of a specific patient advocacy group for brain tumour patients, and for the past 8 years the 2 separate organisations have been arranging annual brain tumour public meetings for patients and caregivers.

■ Scandinavian Neuro-Oncology Group

The Swedish Brain Tumour Study Group also takes part in the Scandinavian Neuro-oncology Group in the framework of collaboration between the Nordic countries in conducting clinical trials and arranging common scientific meetings every second/third year.

■ New Cancer Strategy and Cancer Plan

In Sweden, cancer care has been integrated without any specific cancer centres. Survival rates of cancer patients are high for most tumour types when compared internationally, however, we do also have problems. We see weak coordination in prevention, long and variable waiting times, lack of patient focus, lack of pathologists and radiologists, and, most noteworthy, treatment opportunities are unequally distributed among the population. Therefore, the Swedish government and authorities have decided on a new national and regional cancer strategy, which includes establishment of 6 regional cancer centres with an overall responsibility for the cancer care in their respective regions. The national aspects are especially emphasized. All centres have to lead and coordinate well-aligned patient-focused care processes in cancer, including for patients diagnosed with brain tumours, design a plan for psychosocial support, rehabilitation, and palliative care of good quality, develop support for relatives, introduce a written, individual care plan for each cancer patient, and every patient should have the support of a contact nurse. Patient-related outcomes should be used in the cancer process work and caregivers must have knowledge about a patient's right to a second opinion. The regional cancer centres have an obligation to develop national guidelines/clinical practice guidelines and, most importantly, to implement these guidelines as well. A national clinical practice guideline for malignant brain tumours was finalized in 2012. The centres also have to strengthen clinical cancer research and to optimize the quality and use of national quality registries and biobanks in this research.

This exciting work has just begun and the expectations are high also in the field of neuro-oncology. Members of the Swedish Brain Tumour Study Group are highly involved in this important work for all patients regardless of their position in society or residence.

The Swedish Brain Tumour Study Group will continue its work with a patient perspective for equal and fair cancer care for all patients. There is much more to be done. Therefore, it is important to further improve our cooperation with other national and international organisations as well as to support interdisciplinary collaboration. The new organisation for cancer care gives us a truly good opportunity to continue our work.

Reference:

1. Malmström A, Grønberg BH, Marosi C, et al.; Nordic Clinical Brain Tumour Study Group (NCBTSG). Temozolomide versus standard 6-week radiotherapy versus hypofractionated radiotherapy in patients older than 60 years with glioblastoma: the Nordic randomised, phase 3 trial. *Lancet Oncol* 2012; 13: 916–26.

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