Project Title: Late toxicity and long-term quality of life in head and neck cancer survivors

Overview:

With this project, we will investigate how the treatment for head and neck cancer relates to the quality of life among survivors of the disease 5 years post diagnosis and which toxicities are present. This will be done through patient-answered questionnaires and a clinical examination. Examples of toxicities of interest include dry mouth, difficulty swallowing, difficulty opening the jaws (trismus), soft tissue fibrosis, damage to nerves, injury to the carotid artery, osteonecrosis of the jaws, and dental caries. Examples of quality of life aspects are pain, ability to take part in leisure activities and return to work, ability to perform basic tasks essential to daily living, and emotional state. Comparisons between the patients in this study and a reference population of head and neck cancer patients will be made to see how these factors change from the years immediately following treatment to 5+ years post diagnosis.

This project runs from September 2017 to September 2020. There are two primary investigators (also know as study leads): Professor Susanne Singer from the Institute for Medical Biostatistics, Epidemiology and Informatics in Mainz, Germany, and Professor Vincent Grégoire from the Radiation Oncology Department of Centre Léon Bérard in Lyon, France. Katherine Taylor at the Institute for Medical Biostatistics, Epidemiology and Informatics in Mainz, Germany is the study coordinator.

Goals of the project:

The aim of this study is to identify treatment factors that contribute to or detract from quality of life and identify long-term treatment-associated toxicities for head and neck cancer patients. This project will primarily benefit future head and neck cancer patients.

Why is this project important?

Although there is considerable information about how patients fare within the first few years of treatment for head and neck cancer, very little is known about what clinical and social problems the patients who survive more than 5 years encounter and what kinds of supportive care this group uses or may require. The results of this study will shed light on these issues.

Who can participate?

Patients who fulfil the following criteria are eligible to participate:

1) You must have had a verified head and neck cancer affecting one or more of the following sites: larynx, lip, oral cavity, salivary glands, oropharynx, hypopharynx, nasopharynx, nasal cavity, nasal sinuses, or lymph node metastases from unknown primary tumour in the head and neck area.
2) Your initial cancer diagnosis must have occurred at least 5 years before.
3) You must be able to understand and complete the questionnaires in one of the study languages.
4) You must be able attend the clinic conducting the study in your area/country.
5) You must be at least age 18 years old.
6) You must provide written informed consent.

Where can I find out more about this project or ask to participate?

This is an international project, with multiple countries participating. The countries are: Belgium, Brazil, Egypt, France, Germany, Hungary, Israel, Italy, Japan, the Netherlands, Norway, Poland, Portugal, Serbia, Slovenia, Sweden, and the USA.

If you have questions or comments, you may also contact the coordinator for the entire project, Kathy Taylor at the Institute for Medical Biostatistics, Epidemiology and Informatics in Mainz, Germany at: +49 (0) 6131175186,

or by email at: kataylor@uni-mainz.de

or by post at:

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The information above will be available within the next months in the languages of the other study locations as well.