

String of Pearls and leukaemia, myeloma and lymphoma

Taken together, leukaemia and lymphatic cancers are one of six most common types of carcinoma. In the Netherlands, about 1500 people a year are diagnosed with leukaemia and more than 1100 die of the condition. Lymphatic cancer is one of most prevalent kinds of malignant neoplasm amongst the ethnic-minority population.

These diseases affect all age groups. There is a peak in their incidence in children and young adults, but most new patients are aged between fifty and eighty. Amongst that group, the tumours have almost always metastasised by the time the condition is diagnosed. None the less, the average five-year survival rate for patients aged under 60 with an aggressive form of acute leukaemia or lymphatic cancer is 40 per cent – a result achieved thanks to the use of aggressive interventions such as stem-cell transplantation. The prognosis for older sufferers is less favourable, but new so-called “targeted” therapies with an immunological or molecular basis are beginning to hold out hope for better outcomes in the future.

Leukaemia and lymphatic cancers have a variety of causes, but genetic and molecular damage plays a decisive role. Certain forms – acute leukaemia, Hodgkin lymphoma (MH) and non-Hodgkin lymphoma (NHL) – can in many cases be treated successfully by chemotherapy and/or stem-cell transplants. But others, notably multiple myeloma (MM) and chronic lymphocytic leukaemia (CLL), are chronic. The symptoms and progress of these conditions, and the prognosis for the patient, are determined primarily by changes in his or her DNA. These are almost always interlinked and appear over a period of time, causing normal cells to take on malignant characteristics and eventually to display malignant behaviour.

For String of Pearls, the following diagnostic groups have been defined.

- Acute myeloid leukaemia (AML).
- Myelodysplasia and acute lymphoblastic

leukaemia (ALL).

- Chronic myeloid leukaemia (CML) and chronic lymphocytic leukaemia (CLL).
- Multiple myeloma (MM), also known as Kahler’s disease.
- Malignant lymphoma (Hodgkin lymphoma and non-Hodgkin lymphoma).

Scientific value

Research using the national String of Pearls database and biobank can help to improve our knowledge and understanding of these tumours. As well as encouraging the rapid introduction of new diagnostic techniques and treatment, this could also facilitate the development of therapies tailored to the individual patient according to the genetic characteristics of their tumour.

Dutch research in this field, known as haemato-oncology, is very highly developed. The pioneering Haemato-Oncology Foundation for Adults in the Netherlands (HOVON), a partnership for clinical trials and molecular diagnostics in which all the country’s teaching hospitals are active, is now a prominent player on the domestic and international stage.

Work to improve information, prevention and research around these diseases is under way on a number of fronts, in collaboration with charities like the Dutch Cancer Society, with the country’s eight comprehensive cancer centres and with a number of patient groups: the Leukaemia Contact Group, the Netherlands Lymphatic Cancer Association, the Kahler and Waldenström Patients’ Contact Group and the Stem-Cell Transplantation Contact Group. At the European level,

there is co-operation with LeukemiaNet, the European Myeloma Network, the European Organisation for Research and Treatment of Cancer (EORTC), the European Haematology Association (EHA), the European Bone Marrow Transplantation Group, Eurodonor, EuroCord, the European MCL Network and, through intergroup studies as part of the HOVON trial network, with bodies including the Swiss Group for Clinical Cancer Research (SAKK) and the Medical Research Council (MRC) in the UK. The “pearl” also works with industry, particularly in the pharmaceutical sector, and participates in clinical trials. These alliances sometimes establish biobanks, which may in the future be linked to those affiliated with String of Pearls.

About the pearl

Quality standards for the collection of clinical data and biomaterials for this “pearl” have been formulated in order to ensure that the information is gathered in a uniform fashion. Each participating university medical centre (UMC) is responsible for the quality and completeness of its own data collection and registration.

As well as clinical data and biomaterials, information is also garnered from hospital IT systems and other sources. Because a substantial proportion of patients with leukaemia or a lymphatic cancer take part in clinical trials, an extensive database of clinical information is already available.

The biomaterials collected for research in this field are bone marrow, blood and lymph node biopsies.



The String of Pearls Initiative

The String of Pearls Initiative is the result of a unique partnership between the eight Dutch university medical centres (teaching hospitals). Founded in 2007 by NFU, the Dutch Federation of University Medical Centres, the initiative gathers clinical data and biomaterials from all the participating institutions so that together, they can promote the ad-

vancement of science, improve patient treatment and encourage the development of new products, as well as strengthening the economic position of biomedical research in the Netherlands. Initially, the project is focusing upon nine groups of medical conditions, its so-called "pearls". In the future, its activities may be expanded to include

others. For more information, you can contact the String of Pearls Initiative at info@string-of-pearls.org.