STRING OF PEARLS INITIATIVE

FACTSHEET
HEREDITARY COLORECTAL CANCER

IMPROVING YOUR HEALTH BY SHARING SCIENCE

MAY 2010

String of Pearls and hereditary colorectal cancer

Each year in the Netherlands, about 700 patients are diagnosed with one of the four forms of hereditary colorectal (bowel) cancer, known respectively as HNPCC, FAP, AFAP and MAP. The majority are subsequently treated at one of the Dutch university medical centres (UMCs). Collectively, these teaching hospitals see approximately 400 new patients annually.

The Netherlands is a world leader in the diagnosis, registration and treatment of this group of cancers, and in scientific research into them. Because of the complexity of the care required, the UMCs are working more and more closely with one another in this field. And thanks to that collaboration they have also created well-defined databases and biobanks of sufficient size to enable effective scientific research. Further clustering of this expertise and material should help the Netherlands to maintain its research leadership and to secure a unique place in the vanguard of scientific and clinical work in the field of hereditary colorectal cancers.

Scientific value

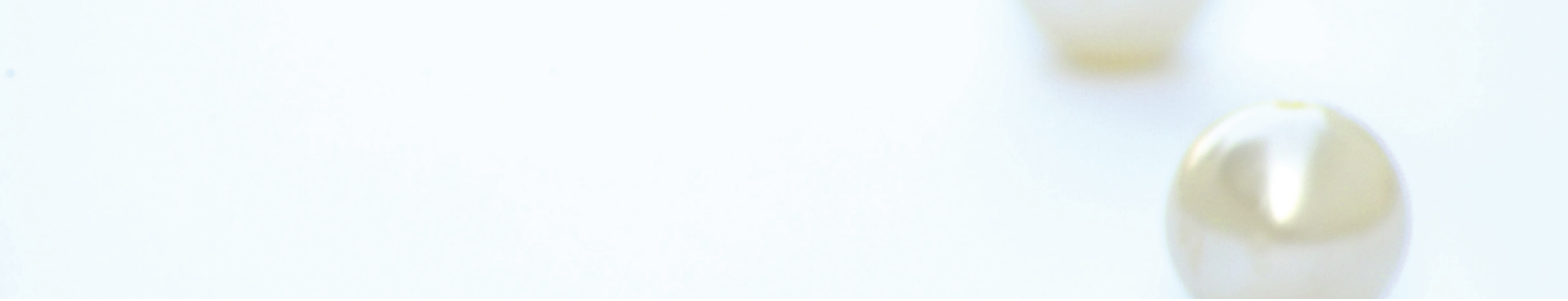
The aim of this "pearl" is to use scientific research to improve the prevention and treatment of hereditary colorectal cancers. In the long term, it also intends to foster psychosocial research. It is hoped that the studies facilitated by the "pearl" will improve the quality and effectiveness of patient care, as well as the implementation of research findings. A national registration system called PALGA has been established to hold the results of pathological tests on almost all Dutch patients with an hereditary colorectal cancer. This provides access to archives containing material originally used for diagnostic purposes, and there will also be intensive collaboration with databases and biobanks. Work to improve bowel cancer information, prevention and research is under way on a number of fronts, in collaboration with charities like the Dutch Cancer Society and the Netherlands Digestive Diseases Foundation, as well as several groups representing patients: the HNPCC Patients' Association, the Polyposis Contact Group and the Dutch Federation of Cancer Patient Organisations. The "pearl" also works closely with STOET, the Netherlands Foundation for the Detection of Hereditary Tumours, and is actively seeking to forge relationships with the biomedical industry, especially small and medium-sized companies operating in its field. As far as we know, there have been no moves as yet to collaborate at the European level on the formation of biobanks for hereditary colorectal cancers.

About the pearl

A number of materials are collected for the biobank: blood for DNA isolation, plasma and serum, intestinal biopsies and frozen and paraffin-embedded samples of healthy and cancerous tissue. For the database, the following patient and case-history information is recorded: demographic data, details of family history, molecular diagnostic data, test results, endoscopy findings, details of surgery, results of microsatellite instability tests and results of molecular genetic tests. As well as the general Dutch standards for the collection of biomaterials, these activities also comply with specific national and international agreements concerning the data collected for research in respect of hereditary colorectal cancers.

Participant privacy

All participant data is subject to the strict rules of patient confidentiality. The donor's name, address and any other personal information from which it might be possible to ascertain their identity is retained by the hospital treating them, where it safeguarded as required by law. This means that it is known only to the medical staff directly involved with their treatment and to the hospital administration, and will never be disclosed to anyone else. The medical data and physical specimens used for research purposes are assigned a unique code, which prevents details being mixed up but also ensures that the person performing the study knows none of the patient's personal details. Whilst the results of the research are likely to be published in scientific journals, for example, those articles will never contain personal information about the participants.



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 advancement 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.