

String of Pearls and inflammatory bowel disease

Inflammatory bowel diseases (IBD) are chronic inflammations of the digestive tract. So far, no clear cause of these conditions has been identified. The two most common forms of IBD are Crohn's disease and ulcerative colitis. Patients suffer chronic abdominal pains, sometimes bloody diarrhoea, weight loss and in some cases anaemia. The majority undergo surgery and spend years on anti-inflammatory medication. The courses of both Crohn's disease and ulcerative colitis are characterised by alternating periods of active inflammation and comparative calm. Patients often develop IBD at an early age, so it can impair their education as well leading to sick leave and incapacity for work in later life. In the Netherlands, an estimated 20-30,000 people are living with an inflammatory bowel disease. As in other European countries, the number of new patients has risen sharply in recent years.

Researchers currently suspect that IBD is caused by a combination of genetic and environmental factors. People with a family history of one of the conditions are at relatively high risk of developing it themselves. In fact, heredity plays a more prominent role in IBD than in other diseases with a genetic component, such as diabetes, asthma and schizophrenia.

Scientific value

Much can be done to improve IBD patients' quality of life, not least by tailoring treatment to their individual needs (personalised medicine). To unravel the genetic aspects of these conditions, research based upon a good patient cohort is essential. A better understanding of what causes the diseases, the effectiveness of the medicines prescribed and the cost-effectiveness of treatment will improve the situation for all sufferers. In addition, it should mitigate the economic loss resulting from future sick leave and treatment costs. For health-care providers, such research can produce clinical and quality indicators for new methods of treatment.

And it could give the pharmaceutical industry a head start in developing and applying drugs for the conditions. Work to improve IBD information, prevention and research is under way on a number of fronts, in collaboration with charities like the Netherlands Digestive Diseases Foundation, as well as national patients' association CCUVN and ECCO, the European Crohn's and Colitis Organisation. The Initiative on Crohn's and Colitis (ICC), an IBD partnership between the eight Dutch teaching hospitals, is already at an advanced stage in its preparations to establish a biobank. Moreover, the String of Pearls biobank model is now being exported successfully to other European countries under the auspices of the ECCO Biobank Initiative.

About the pearl

Clinical data is gathered in accordance with strict guidelines. In collecting, storing and recording biomaterial, the legal requirements of good clinical practice (GCP) and good laboratory practice (GLP) are observed at all times. The DNA database will hold genetic markers known to

be associated with a risk of IBD.

GLP and GCP standards are applied to the quality, data definitions and collection of materials for this "pearl". Information about the progress of the conditions is recorded using internationally accepted scoring systems. In the case of Crohn's disease that is the Harvey Bradshaw Index, whilst the Simple Clinical Colitis Activity Index is used for ulcerative colitis. For studies of genetic markers, the Montreal Classification will be applied. As well as clinical data, pseudonymised as per String of Pearls rules, the following biomaterials are collected: blood, intestinal biopsies, DNA, faeces and resection material. In each case the time and date of collection are recorded, together with the nature of the medium, the protein concentration and the DNA or RNA, all in accordance with the quality guidelines compiled by String of Pearls. As well as guaranteeing quality, this ensures that material and data from different sources can be pooled for research purposes.



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@parelsnoer.org.