

## String of Pearls and rheumatoid arthritis and arthrosis

Arthritis is a collective term applied to more than a hundred distinct disorders affecting the body's locomotor apparatus. About 1.5 million people in the Netherlands suffer from some form of arthritis, with common symptoms including inflammation of the joints, stiffness, pain and fatigue.

Generally speaking, these conditions are seen more often in women than in men and are more likely to affect older people than the young. Currently, most forms can be treated but not cured. Such disorders of the locomotor apparatus are one of the leading causes of lost working days; according to the most recent estimates by research institute TNO, arthritic conditions cost the Dutch economy €2.1 billion in 2006. Due to an ageing population, increased obesity, lack of exercise and unhealthy lifestyles, the number of sufferers is expected to increase.

Initially, String of Pearls has set up biobanks for two forms of rheumatic disease: rheumatoid arthritis and arthrosis. Through these, the initiative hopes to further strengthen the leading research position currently held by Dutch rheumatology. There should also be economic benefits, building upon the existing widespread collaboration between university medical centres (UMCs) and the business community in this field. Nowadays, treatment of these potentially incapacitating conditions begins as early as possible, since the best results are obtained by preventing the onset of long-term invalidity.

For String of Pearls, the following diagnosis groups have been defined:

- **Arthrosis:** the degeneration, and in some cases the complete disappearance, of the cartilage between the joints. More than 1.2 million people in the Netherlands have this condition.
- **Rheumatoid arthritis:** an autoimmune disease that causes inflammation of the joints. There are about 290,000 patients in the Netherlands.

### Scientific value

All eight Dutch UMCs provide information on the following matters for this "pearl".

- **Recent-onset rheumatoid arthritis:** identification of risk factors for persistent and temporary inflammation and for erosivity.
- **Arthrosis:** identification of risk factors for invalidity, cartilage damage and structural changes.

For patients, this "pearl" means better care and more effective treatment. Since it will help scientists to gain a better understanding of the processes which lead to deformity of the joints and invalidity, there is a greater chance that they will be able to develop improved therapies. This will eventually be the largest patient cohort of its kind in the world, thus enabling the identification of even relatively minor risk factors for these diseases and their progression.

Work to improve information, prevention and research around these conditions is under way on a number of fronts, in collaboration with the Dutch Arthritis Association charity and with the Arthritis Patients' Association. Six of the eight Dutch UMCs, plus a number of satellite centres, are participants in CHECK, a unique global cohort of patients – 100 from each institution – with early arthrosis.

In the case of rheumatoid arthritis, experience is drawn from the Leiden Early Arthritis Clinic and other sources. Most of the UMCs conducting research in this field maintain intensive relationships with the pharmaceutical and biotechnology industries – companies like Abbott, Wyeth, Roche, Schering-Plough, Centocor, Celera and Philips. Thanks to its cohorts,

the Netherlands is one of the world's five leading nations in scientific publications on rheumatology. Within Europe, Leiden University Medical Centre is the co-ordinator of Masterswitch, a European Integrated Project under the EU Seventh Framework Programme. Dutch institutions also participate in numerous EULAR Study Groups.

### About the Pearl

Included in this "pearl" are all Dutch cases of non-traumatic arthritis – septic arthritis and crystal arthropathy excepted – diagnosed within two years of symptoms first arising. The records thus include cases affecting the joints of the hand, the foot, the back and other parts of the body. National agreements have been reached about the clinimetrics (measurement of clinical symptoms) used, as regards both the activity of the disease and damage parameters.

Arthrosis, when cartilage disappears or its quality changes, may also result in inflammation of the joints. In this form it can be difficult to distinguish from, say, rheumatoid arthritis. It is hoped that the String of Pearls cohort can help to clarify the differences between such conditions.

As well as pseudonymised information from the patient's medical record, the database and biobank also include scan images, DNA and serum. Having been implemented for the CHECK cohort, sound national agreements covering these materials are already in place. As long they meet the required quality standards, the existing biobanks will be adopted by the String of Pearls Initiative.



## 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](mailto:info@string-of-pearls.org).