



FACTSHEET

NEURODEGENERATIVE DISEASES

IMPROVING YOUR HEALTH BY SHARING SCIENCE

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String of Pearls and neurodegenerative diseases

Most types of dementia are neurodegenerative disorders. This “pearl” is concerned with the early phase of the condition, especially in its most common form, Alzheimer’s disease, and its precursors, known as mild cognitive impairment (MCI). Dementia is most widely prevalent in the elderly; about 30 per cent of the over-80s are sufferers. This makes advanced age the principal risk factor for developing the condition. With the Dutch population ageing rapidly, it also means that dementia is set to become a far more serious public health issue in the near future. The number of patients is forecast to rise from 200,000 in 2005 to more than 430,000 in 2050. Dementia also occurs in younger people – here defined as those aged under 65 – although the causes and symptoms in this group tend to be different, with a relatively high incidence of particular forms, such as corticobasal degeneration (CBD) and certain rare hereditary disorders.

Alzheimer’s disease is characterised by the progressive onset of memory problems, eventually followed by general cognitive decline. In its advanced form the condition causes a complete loss of independence, so that there is often no choice but to admit the patient to a nursing home. Current treatments only address the symptoms of the disease, not its underlying causes. Apart from Alzheimer’s, other conditions leading to degeneration of this kind include dementia with Lewy bodies (DLB) and frontotemporal dementia (FTD).

Scientific value

The aim of this “pearl” is to establish a biobank containing material – blood, brain scans and, if possible, cerebrospinal fluid – collected from patients with discernible cognitive problems, as well

as a database of clinical information about them. The structure of the standardised patient cohort will facilitate the development of diagnostic methods, treatments, medicines and scientific research into the origins of neurodegenerative diseases. Because data about a patient’s specific characteristics makes it possible to personalise their treatment, it should also improve the effectiveness of medical interventions.

About the pearl

At the heart of this “pearl” are so-called “biomarkers” and the question of their value in predicting and diagnosing the onset of dementia, particularly in the form of Alzheimer’s disease. Such biomarkers could be extremely important in determining how the condition unfolds and how effective the medication used to treat

it actually is. In the case of patients not suffering from dementia, the key issue is whether and how that symptom develops. For those in whom it has already appeared, the focus is upon the rate of their further cognitive decline. The data and biomaterial for the “pearl” is collected from patients deemed competent to consent who have been referred to the memory clinic or a similar unit of a university medical centre (UMC). Subjects must be experiencing demonstrable cognitive impairment, with a clinical dementia rating (CDR) of 0.5 or 1 and a mini-mental state examination (MMSE) score of 20 or higher. The biobank contains blood and cerebrospinal fluid collected from these patients. MRI scans of their brains are also held.



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.