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EDITORIAL

Alzheimer disease: The next challenge for individuals with Down syndrome

La enfermedad de Alzheimer: El próximo desafío para las personas con síndrome de Down

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The significant rise in life expectancy in individuals with Down syndrome (DS), which has gone from less than 10 years to more than 60 over the last century, has changed its epidemiology radically. Most individuals with DS are currently more than 18 years old. As in the general population, aging is linked to new health problems. Adults with DS, their families and caregivers are often unconscious of this and health professionals also feel unprepared. From a social point of view, the fact that this is happening in a context of great vulnerability adds another issue to the problem. The main caregivers – their parents (or siblings) in many cases – are themselves in a fragile situation because of their advanced age, while the institutions are unprepared to handle this problem. All of us (families, caregivers, physicians, politicians, etc.) should be aware of the magnitude of the challenge.

Among the illnesses associated with aging in DS, Alzheimer disease (AD) stands out. Towards the age of 40 years, practically all the individuals with DS present the neuropathological findings of AD in the brain. By the time they are 65 years old, 80% of those with DS will have developed dementia from AD. The cause of this strong association lies in the extra copy of the amyloid precursor protein gene, located in chromosome 21. All these facts have led to the conceptualisation of DS as a pre-symptomatic stage of AD. Nevertheless, diagnosing AD is especially complex in DS due to the many intellectual disability variable linked to DS and

their different presentations. Memory problems (the most frequent complaint in the general population) are rarely the reason for consultation. Instead, neuropsychiatric changes or deterioration in functionality are what give rise to seeing a physician.

The realisation that AD constitutes the main health problem for the adult with DS led the Catalanian Foundation for Down Syndrome Down (FCSD in Spanish) at the Down Medical Centre, in collaboration with the memory unit at *Hospital de la Santa Creu i Sant Pau (HSCSP)*, to set up a specialised DS and AD unit. This unit will centralise attention to all the neurological problems associated with DS for all the residents in Catalonia. A world-pioneering clinical investigation programme to ascertain the natural AD history in the subjects with AD, the "Down Alzheimer Barcelona Neuroimaging Initiative" (DABNI), will complement the health programme. The DABNI clinical investigation programme is offered to all adults with DS included in the health plan. The programme consists of an intensive biomarker study, including research magnetic resonance imaging, positron emission tomography scans, spinal taps and blood and genetic analysis, as well as sleep studies with polysomnography.

It is essential to advance in clinical research into AD in DS if we want to repeat the success that we have achieved in the past to improve the health and quality of life for individuals with DS and their caregivers.