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ABSTRACT: *Our experience of the EDS disease is based on a cohort of 2300 cases. First descriptions of Dermatologists (Tschernogobow, Ehlers, Danlos, Miget) have strongly oriented the diagnosis on two signs: joint hypermobility and skin stretchability. Therefore hiding other clinical expressions with a much more severe impact on the life of the patients: proprioceptive disorders, dysautonomia, disorders of the sensorial functions, hemorrhages, cognitive alterations, psychopathological manifestations. Despite its high level of prevalence, the EDS is still largely unnoticed by physicians. The delay for diagnosing an EDS case is in 21 years. The most frequent forms don't have a genetic identification. The absence of diagnosis is at the root of a chaotic medical process with a medical drifting from specialist to specialist. Among social consequences we find dropping out of school and exclusion from work and social life. In lack of diagnosis, these patients are also excluded from new forms of emerging treatments (orthesis, oxygen therapy, local proprioceptive pains treatments, adapted physical therapy...) and often victims of iatrogenia.*

"Listen to your patient; he will give his diagnosis" (Sir William Osler).

Ehlers-Danlos syndrome, Hypermobility syndrome, disability, Iatrogenia, hereditary disease, rare disease

Our experience of the EDS (Hamonet, 2012) disease is based on a cohort of 2300 cases (children and adults with 80% female cases), collected between 1988 and 2015. All these patients have been selected according to the criteria of the international scientiýc community evidencing signs of fragility of their skin and other connecting tissues, including joint hypermobility, together with various joint disorders connected to proprioceptive deýciencies. They are treated with new and original therapies (Hamonet, 2015) such as oxygen therapy, proprioceptive orthesis including speciýc compressive garments (Hamonet, 2014).

The EDS disease has been identified based on three descriptions made by three dermatologists, Tschernogobow (Moscow, 1892), Ehlers (Copenhagen, 1900) and Danlos (Paris, 1908). The current name originates from Miget (Paris, 1933) who was the first in his medicine thesis to link two of these precursors to name the disease. These first descriptions have strongly oriented the diagnosis of this disease on two signs; joint hypermobility (Grahame, Bird, & Child, 2000; Beighton & Horan, 1969) and skin stretchability. Since then, in current medical practice, diagnosis of this pathology will be almost exclusively based on these two signs, often without important functional consequences (actually hypermobility often allows for notable physical performances for children and teenagers), therefore hiding other clinical expressions with a much more severe impact on the life of the patients, including various disabling situations.

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The severity of this disease and its best diagnostically signs are:

- Proprioceptive disorders sometimes responsible for very severe difýculties of motor control (pseudo palsies), widespread, acute pain, resisting to "*pains killers*", important breathing difýculties.
- Dysautonomia (Bravo, Sanhueza, & Hakim, 2012) with instable blood pressure (mainly hypotension), thermoregulation and vessels motricity disorders, tachycardia crisis, considerable fatigue, digestive and bladder dysfunctions.
- Disorders of the sensorial functions blurring the perception of external environment.
- Hemorrhages.
- Totally unnoticed cognitive alterations (memory, attention, orientation), likely a secondary effect of the dysfunction of proprioceptive function (acting almost as a sixth sense) complete, together with some psychopathological manifestations, a framework of multiple functional disorders.

Despite its high level of prevalence, the EDS is still largely unnoticed by physicians. Most of them connect the syndrome with their own ýeld of specialization, i.e. rheumatology (ýbromyalgia, spondyloarthritis, arthrosis), neurology (multisclerosis), respiratory diseases (asthma) and, in particular, psychiatry (depression, bipolar state, though there is a link between EDS and autism). Cases of autism with clinical signs of EDS have been observed in a same family. The absence of easy to use genetic tests confounds physicians in their identiýcation of EDS as they lack conýdence in clinical practice, mostly based on the subjectivity of the patient. Patient subjectivity

is today not taken into consideration by a medicine which prefers objective testing such as medical imaging or biological testing. Geneticists themselves who are often involved in diagnosing this hereditary disease will typically restrict their answer to a "*possibility or likeliu -1.2 TDsrest5(ofa)0.5EDS,"*