

# Barcelona-based Neurosurgical Specialist Awarded Designation of International Center of Excellence for Ehlers-Danlos Syndrome

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The International Ehlers-Danlos Society recognises the clinic of Dr Vicenç Gilete, Barcelona neurosurgeon, as the first and only Center of Excellence in Spain.

Designated by the International Ehlers-Danlos Society as a Center of Excellence, Dr. Gilete's clinic is the first and only Center of Excellence in Spain and so far, the only recognised Center of Excellence that also provides surgical treatments in Europe.

Ehlers-Danlos Syndrome (EDS) is a rare disorder that affects the whole body. It is a disease affecting the structure of collagen; collagen makes up the tissues in our bodies. The most common symptoms are joint hypermobility and generalized pain. As symptoms can present throughout the body (multi-systemic), patients often struggle finding the right specialist for a diagnosis. Studies have shown that the average time between onset of symptoms and diagnosis is 10 years. Patients see a variety of doctors for the many different symptoms they experience. Few doctors are experienced in patients with EDS and its complexities.

A small percentage of patients with connective tissue disorders (such as EDS) can present with severe brain and spinal conditions due to the laxity of their tissues. The neck may become too weak to hold up the head, a condition called Craniocervical Instability (CCI). In some cases, the bottom of the spinal cord may become stuck to the wall of the spinal column and pull down on the spinal cord, a condition called Occult Tethered Cord (OTC).

Additionally, in rare cases, patients with post-viral diagnoses such as ME/CFS or long COVID present with similar issues. These conditions are not common in the general public and are therefore not easily diagnosed, even by experienced neurosurgeons. The diagnostic tools necessary for these diagnoses are not conventional scans.

Dr Vicenç Gilete began treating complex spinal and brain conditions in patients with Ehlers-Danlos Syndrome (EDS) beginning in 2015. By 2018, his reputation spread internationally and treating this very niche complex population of patients became the full focus of his practice. Patients come from all over the world to seek out Dr Gilete's opinion and expertise for these uncommon brain and spinal disorders. They find out about him either through online patient advocate groups or from referrals from their local healthcare team. He has presented at international conferences, provided trainings to other medical professionals, and sat on expert roundtables.

Leading up to today, thousands of patients from around the world have contacted Dr Gilete for his expert opinion. 90% of patients seen either in person or via telemedicine consultation come from countries outside of Spain. Currently Dr Gilete is the only dedicated neurosurgical specialist in Europe. There are only a handful of neurosurgical specialists in the world dedicated solely to these types of patients. The other centres are located principally in the United States.

After nine years of serving these patients, Dr Gilete has formed relationships with other specialists, initially to support patients coming to Barcelona for surgery. As complex patients present with many comorbidities (conditions related to their primary diagnosis), it is important to treat the whole patient. Cardiologist, internist, rheumatologist, radiologist, neurophysiologist, ophthalmologist, and mental health specialist are important members of the team.

As these neurosurgical conditions require unconventional scans to diagnose, **Dr Gilete has formed a special relationship with neuroimaging diagnostic centres** that allows patients to undergo testing in the same trip as a consultation. For ill patients coming from long distances, this facilitates the process of diagnosis. The diagnostic package offered is unique in the world and specifically adapted to delicate patients and these challenging diagnoses.

As a designated EDS Center of Excellence, the only Center of Excellence offering also surgical treatments in Europe, Dr Gilete and his team look forward to continuing to provide compassionate experienced service to this community of underserved patients. He hopes to apply the experience gained from working with patients and other professionals to expand services beyond neurosurgical services, establishing a multidisciplinary centre where patients with EDS and other similar conditions can find integrated answers and treatments to the variety of health issues from which they suffer.

Media:

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Charities & non-profits :: Coronavirus (COVID-19) :: Health

## Related Keywords:

EDS:: Ehlers-Danlos:: CCI::
Tethered Cord:: ME/CFS:: Long
COVID:: Craniocervical
Instability:: Atlantoaxial Instability
:: Neurosurgery:: AAI:: Rare
Diseases::

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