

el Periòdic News

DEMAND FROM THE GOVERNMENT REGARDING MINORITY DISEASES

AMMA



Members of the Association of Minority Diseases of Andorra.

The AMMA calls for a national registry to guarantee diagnosis

The association estimates that there are up to 5,000 unidentified cases due to a lack of official data

ELENA HERNÁNDEZ MOLINA
ESCALDES-ENGORDANY

The Association of Minority Diseases of Andorra (AMMA) is once again putting on the table the urgent need to create a national registry of minority diseases. Five years after its foundation, the entity reiterates that this tool is «essential» to detect and treat people affected by these pathologies, often seri-

ous, chronic and disabling, but little known and difficult to diagnose.

«The lack of a registry is an obstacle that prevents us from knowing how many people are actually living with a minority disease in Andorra,» says Meritxell Benito, president of the association since a month. Benito highlights that, according to estimates based on registries in countries with similar systems,

The registry in question would operate with the support of the administration, doctors and the association

up to 7% of the world's population could suffer from a minority disease. «Therefore, if we extrapolate this data to Andorra, we are talking about around 5,000 affected people who are not identified», she assures.

The AMMA's main request is that the registry become a public and systematic tool to collect data on the diagnosis, monitoring and evolution of patients with this type of pathology.

PEXELS



Association of Minority Diseases of Andorra

"The lack of a registry is an obstacle to knowing exactly how many people are diagnosed"

"If we extrapolate the global data to Andorra, we can talk about around 5,000 people affected"

"It is not a budget issue, because it is compensated by the advantages in public health and quality of life"

"No territory can understand a rare disease if it is viewed in isolation, data must be added to understand"

"We are talking about people who can have a better quality of life not only in clinical terms, but also in social terms"



With an active registry, it would be possible to offer palliative treatments, stop the progression of diseases and anticipate changes

The association remarks that the cost of implementing it should not be an impediment: «It is not a budget issue, because the cost is offset by the advantages in public health and quality of life», the entity explains, citing data presented on April 1st in the program 'Avui serà un bon dia' on RTVA.

The operation of this registry, as explained by the AMMA, would be based on collaboration between the health administration, medical professionals and the association. The aim is to identify the social determinants of health, plan preventive and care actions, and place the patient at the

center of any healthcare decision. It all starts with a key piece of information: diagnosis. "Diagnosis should be the first right of any patient", the association argues, which denounces that this is often not funded in adults.

The registry would allow one of the main paradoxes of Minority Diseases to be overcome: although each disease affects few people (one in 10,000, on average), all of these pathologies affect up to 7% of the global population. "No territory can understand a rare disease if it is considered in isolation; data must be added to understand and address it with guarantee-

THE FIGURES

7%

Minority diseases affect one in every 10,000 people, that is, 7% of the world population.

5,000 CASES

According to AMMA Andorra, there could be up to 5,000 cases of these pathologies.

1,100 EUROS

Genetic tests to detect a disease range between 200 euros and 1,100 euros.

es", the association of minority diseases explains. What is claimed is that with an active registry, there would be the possibility of offering palliative treatments, stopping the progression of diseases, anticipating changes and needs and, ultimately, guaranteeing a more dignified life for patients. «We are talking about people who can have a better quality of life not only in clinical terms, but also social and educational», conclude the association. Therefore, the entity is willing to work together with the institutions to make this instrument a reality that, they assure, «cannot wait any longer». ●

Your leading real estate agency in Andorra.

Our experience guarantees results, realtors since 1988.



📞 (+376) 353 424 / (+376) 379 769

📞 (+376) 747 747

✉️ laportella@andorra.ad

📍 Casa Nova Olivet 10 · Ordino

🌐 www.laportella.ad