Daniel-Anibal Garcia Diego â?? President, FEDHEMO, Spain

> Spain is in the top tier of countries in terms of treatment [for haemophilia] and we are one of the leading countries in Europe for human haemophilia patients in clinical trials for new drugs.

21.01.2019

Tags:

Spain, Haemophilia, Association, FEDHEMO

Daniel-Anibal Garcia Diego, president of the Spanish Haemophilia Federation (FEDHEMO), discusses the current situation of haemophilia treatment and healthcare coverage in Spain, as well as the unique challenges created by the autonomous regions of the country. He also gives insight into FEDHEMOâ??s ongoing initiatives and future objectives.

Haemophilia is often referred to as an â??invisible diseaseâ??, affecting one in 10,000 people globally. Could you begin by giving an overview of haemophilia in Spain?

We have 350,000 diagnosed patients with haemophilia in Spain, a number which could rise to over 400,000 including undiagnosed patients. However, Spain is in the top tier of countries in terms of treatment and we are one of the leading countries in Europe for human haemophilia patients in clinical trials for new drugs.

How would you assess Spanish haemophilia patientsâ?? ability to access medication?

We have quite a complex system due to the decentralized autonomous regions of Spain. To create patient access, we must go through the Ministry of Health (MoH), then achieve market access approval in the regions, and in some cases, we have to pass the committees in the hospitals. It may not be the easiest or the fastest system to navigate, but Spanish patients have good access to new drugs and we have a large number of patients in the profile access scheme. Spain also has a lot of patients using both recombinant and plasma-derived products. As I mentioned before, we also have a high number of patients in clinical trials.

Is haemophilia being treated as a priority by Spainâ??s MoH? What can be done to improve the situation?

There is a high awareness of haemophilia as a disease, both from the society and from the industry players. However, I think we still need to raise awareness of the benefits of treatment and the importance of using the best drugs and clinical approaches to treating the disease. We need to assure all players and regulators that they will have a strong return on their investment.

Can you give an overview of FEDHEMO and its activities?

We have more than 20 chapters that operate in three main areas. The first is organizing summer camps and workshops on a national level. The second area is to act as a support network for all our chapters and the third is our advocacy work, lobbying for haemophilia patients. FEDHEMO is really focusing on trying to obtain the best drugs and the best access for the patients. FEDHEMO wants to ensure that patients with haemophilia in Spain have the best quality of life as possible and become more normalized.

The 17th of April was World Haemophilia Day. What were some of the incentives organized on this day in Spain?

We are using the same model as the World Federation of Haemophilia (WFH). FEDHEMO is trying to explain to society that the healthcare system, industry players, and physicians need to create tailored approaches because the disease is different in each patient. We are trying to move from how the disease will change peopleâ??s lives to how we need to change the treatment so that people donâ??t need to change their lives. We also need to focus on childhood haemophilia and families with young children who have the disease. In some cases, haemophilia also affects the sexual life of females. We need to explain that haemophilia also has a social aspect. The World Haemophilia Day motto is â??sharing knowledgeâ?• because the most important thing is not the disease itself, but the lives of people who have haemophilia.

Access to innovative medicines is a challenge in Spain due to the separation of the healthcare system through autonomous regions. What is FEDHEMO doing to combat this challenge?

We are working closely with our chapters to create a universal approach at both the national and regional levels. Through working closely with the regions, we are trying to think outside of the box to explore new ways to find drugs, create review processes and develop pricing schemes. We want to make it easier for patients to gain access to new drugs. FEDHEMO is also working with the MoH to create new regulations and decrees. Together we are creating a more innovative framework, one that will allow the introduction of new drugs in the future.

We are trying to explain the real value of drugs to pharmacies and patients through patient reports. We are trying to explain to pharma companies the real patient experience of individuals with the disease. To change the approach, you need to offer drugs that fit the needs of the patients.

Of course, pharma is introducing quite a lot of data in clinical trial reports. They are also creating new programs and new material that will make a point of focusing on the patientâ??s experience in other aspects.

Nowadays there are over 50 clinical trials open in Spain and we have some clinical trials in gene therapy here as well. We are in the top tier of countries for clinical trials. For patients, we are pushing and trying to educate and train people about the benefits of participating in clinical trials.

You have been president of FEDHEMO for the past three years; have you achieved everything you set out in your mandate?

No, because there are some severe haemophilia patients in Spain without the possibility of being on profile access schemes. One of FEDHEMOâ??s area of focus is that every single patient with severe haemophilia has the possibility of being involved in a profile access scheme. Also, Spain still has some inequalities between the regions. The situation needs to change so that every single patient in all the regions has the possibility of using the best drugs and accessing the best therapeutic approaches.

You have been at the Federation for nearly ten years, first as the secretary general. What has been your greatest achievement so far and what is next in the pipeline for FEDHEMO?

Well, every single step towards obtaining habilitation for haemophilia is valuable. But our biggest achievement has been that although Spain suffered one of the biggest financial crises in Europe, and maybe in the world, the crisis did not affect the treatment of haemophilia patients in the country. It was not easy, but I think this was a great achievement.

I donâ??t know if I will be the next president of FEDHEMO because we do not have a traditional president-centred orientation. We have a strong board of directors which I work very closely with. But

I think the next objective for the following years will be to create a framework that will allow people with haemophilia in Spain to access the best drugs. We also want to establish a strong formalized system that will allow Spain to be able to fund non-factor and non-replacement therapies. We need to start to work on a new framework that will allow us to use the newest drugs; the drugs of the future.

See more interviews