# Interview: Alicia Folgueira LÃ³pez â?? General Manager Spain & Portugal, Alnylam

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*Alnylam, pioneers in*

*the RNA interference field, seek to bring their revolutionary medicine across Europe, and in particular Portugal before 2020. In this interview the new General Manager for Spain and Portugal, Alicia Folgueira Lopez, a rare diseases authority, discusses how to build an affiliate from scratch, the synergies across the Iberian Peninsula, and the importance of keeping focus.*

**Would you be able to introduce the company and its revolutionary vision to readers?**

Alnylam is a relatively new company to the commercial environment in Europe, although it has existed for more than 15 years in the United States as an investigator company with a specialty in R&D. With any investigator company, there always comes a moment when we face a crossroads, and we must decide whether to continue as a pure investigator a company or take the leap, accept the challenge and bring the final product directly into the hands of the patients. This is the decision we made. Therefore, when the first molecule, Patisiran started to become a reality, and a final solution for patients, we decided to take on all the processes from access to markets, production, and all the commercial and medical affairs tasks. Upon transitioning to become a commercial company, the decision also became global, hence the opening of the affiliate in Iberia.

**The affiliate is only a year old, how has the global vision trickle down into Portugal?**

I was the first Iberian employee for Spain and Portugal, and we began from scratch â?? without an office of employeesâ?? it was an adventure, and it continues to be so. We now have nine employees with the target by the end of the year to reach at least double figures. Things are changing very quickly as we strive to find where the diseases we target are managed in hospitals across Iberia. In Portugal, this is more evident, because two large hospitals manage ultrarare disorders, whereas in Spain we continue our investigations at length given that Spain is a bigger geography and has more autonomous regions.

**To what extent is managing an Iberian operation advantageous?**

Having eyes on both markets does render the affiliate more efficient, and regarding synergies, we can use the expertise of key opinion leaders and experts on both sides to help develop our strategy. Nevertheless, health policy organization is the polar opposite in each country. In Portugal, the system is incredibly centralized whereas Spain is renowned for its decentralized processes.

Concerning health policy and market access, each state has their particularities. However, we work together with all European affiliates under Alnylamâ??s guise in bringing our new medicines to market.

**What is the status of the development of the medicine to Patisiran?**

It is under the approval process with accelerated access. We expect to have it approved soon after summer. Once we have EMA approval we will begin pricing and reimbursement processes with each country, where we are ready for each countries specificity; we know that Germany is fast and Spain and Portugal are slower and more complicated.

The market access environment is complex in both countries. The economic situation in both countries is a challenge, and we need to be aware of the role we can play in promoting the sustainability of the healthcare systemâ??one of our key mission statements. On the other hand, we need to support research on real diseases and increase their awareness. Orphan drugs is a very risky subsector to investigation, and it takes the same amount of time to discover a molecule for rare disease as it would do for any other massive disease in oncology for example. The only way we can sustain this developmentâ??bearing in mind that orphan drugs target far fewer patients, we must ensure that both realities arrive at a viable agreement that sustains both realities.

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**How do you position the company in this environment?**

Innovation solutions for patients who have nothing is our vision and all we do works towards this goal. However, this is more than just innovation; we operate a revolution because our medicines aim to improve lives of patients who have no one else to turn to. Alnylam offers life-changing therapies, not only for patients but families and friends supporting patients. Furthermore, the patients we target are small in number; therefore, we operate a personalized and hands-on approach.

**To what extent is the government open to dialogue on innovative access medicines and their treatment?**

Naturally, the type of conversation that we have with the government regarding extremely rare diseases is not the same as a dialogue on highly prevalent diseases, but I would agree that the government is open to discussion and willing to implement ideas put forward by the industry, when appropriate. Notwithstanding, given the sporadic nature of the diseases that we tackle, there is very little prevalence data and information regarding the demographic; therefore, we have to see on the ground where the patients are per country.

**How does Alnylam work towards raising awareness of these diseases?**

Beyond increasing awareness and improving data is expanding knowledge and the improvement of diagnosis. It is not uncommon for a doctor to be presented with an exceptional patient case suffering for one of the diseases that we treat which the doctor has not studied for at university. If we do not specialize in these diseases and raise awareness amongst doctors and healthcare professionals to better identify the symptoms earlier and refer the patient to a specialist, then the patient is at severe risk. The average time for a patient to receive the correct diagnosis in our field is ten years â?? and sometimes we do not have that amount of time to play with!

We have a lot of work to do in Portugal especially because the prevalence is very high here for Amyloidosis. Diagnosis is always a challenge, and as a stakeholder in the rare diseases community we must improve the diagnostic process and reduce the time to diagnosis. The most important day in the life of a registered patient is the day that the patient finally understands what disease he or she suffers from.

**What incentives do you undertake to increase the promotion of knowledge?**

Medical education is a key priority, and as such we are present at the official conferences, we organize courses, and we collaborate with scientific societies across the nations in which we operate. Our strategy is clearly established: to be tackling amyloidosis and our other rare disease areas will follow.

We are present at the official medical education in congresses and working meetings, not only in the focused working groups but also in the European Academy of Neurology. We also offer genetic testing in the centers that are not able to perform this by themselves, and we support researchers.

**What strengths does Portugal put forward as a place to develop rare medicines?**
Firstly, I would like to point out that Portugal will be at the center of the strategy globallyâ??the eye of the hurricaneâ??because it is the most common country worldwide for ADD disease. Portugal has five times the patients in Spain for the same condition.
Portugal is an exciting country to develop commercially because it is well organized in reference centers. The efficiency you can achieve in Portugal with this organization is very interesting, and therefore, the possibility of developing new referencing centers is positive.
**What are your strategic priorities for the next five years?**
Ensuring access for all patients in need of our drug is our top priority, and along the way, we will increase diagnosis rates to provide early treatment and avoid the worsening of the situation â?? both neurologic and cardiology symptoms. And finally, we intend to differentiate Alnylam based on the platform on which the company was initially established; that of RNA interference; because silencing the genes and stopping the production of the protein is very different to solving what is wrong when the protein is combined with medicines. This is a never seen before medication, and we are the first RNA interference medicine providers worldwide. This advanced technology it is the difference between cleaning the water on the floor or turning off the tap.
[related_story]
**What keeps you motivated on a daily basis?**
Creating the conditions for patients to live worthwhile lives brings me tremendous motivation, mainly because the unmet need in this disease area is enormous. The disease is horribly debilitating, and the process from initial symptoms to death can be as little as five years.
We recently saw a video of a patient undergoing a clinical trial in Spain who went from having no strength in her hands to living a more or less normal life. This dramatic improvement was made possible following the use of our medication. When this patient told us that she owes us her life, I knew at that moment that we do and our medicine makes a real difference.
**What advice would you give to your younger self?**
Learn as much as you can, apply experience, knowledge and never lose the focus. Being able to establish the right expectations concerning timings is essential therefore keep calm, donâ??t lose the focus and go for it!

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