Interview: Consuelo Martín de Dios – Director, Fundacion Instituto Roche, Spain



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Consuelo Martín de Dios, managing director of the Roche Institute Foundation discusses the legacy and movements of the organization as well as the challenges, opportunities, and future of Personalized Precision Medicine in Spain.

What is the background of the Roche Institute Foundation in Spain? What have been the key milestones achieved by the foundation during its history?

The history of the Roche Institute Foundation began in 2004 when the Roche Spain affiliate began to direct attention towards the future of healthcare through Personalized Precision Medicine (PPM). At the time, individualized medicine in Spain was in what could be considered its most primary stages. It was decided it was time to establish the foundation to generate discussion and promote debate about the field. The mission of our foundation is the development of PPM knowledge throughout society, politicians, administrators, and industry stakeholders.

The foundation has reached many milestones since its introduction in 2004. Over several years we have develop training courses and educational symposia partnered with several scientific Societies as the Spanish Society of Medical Oncology, published a genomics encyclopedia alongside the Inter-University Chair in Law and the Human Genome, and developed several publications as a practical guide for the use of biological samples. Additionally, we have contributing to the knowledge of patient associations, as an example regarding the participation on clinical research,

as there are new laws that it states that patient representatives must take part at the clinical trials ethical committees .

Our most recent breakthrough is our published report of recommendations for creating a movement around the putting together of a national strategy of PPM. While there have been some initiatives throughout the regions of Spain, we are still lack a unified, national plan. There is clearly a need for a holistic approach to the evolution of genomics, which is something that we are still very much waiting for.

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What are the main take-aways from the report recently published by the Roche Institute Foundation on the state of play of PPM in Spain?

The report was published as a call to action for the health stakeholders and specially health authorities. We wanted to convey the importance of having the singular blueprint that is necessary to drive the progress of PPM forward. Six key areas are identified in the report, which must be given vital consideration in this future plan. Due to the intimate nature of individualized medicine, the importance of security and governance for a wide spread genomics program is outlined. The report emphasizes the advanced level of training and communication that is needed to integrate an advanced initiative such as PPM. Next, the report highlights how new findings must be translated and organized within the current healthcare system.

The importance of collaboration and coordination among Spanish medical institutions also had to be addressed. This is an area that could be problematic, as health responsibilities are transferred to the regions. A system based on shared information is the only way to achieve an efficient network of universal storage, analysis, and information access. And of course, the last point in the report is a reminder to stakeholders that research and continuous innovation is what will lead the genomics field forward.

What is your assessment of the acceptance and usage of PPM in Spain compared to other markets?

While current Personalized Precision Medicine initiatives around the country do exist, there is still a long way to go in order to reach the goals we hope to see in the future. Some hospitals have already established programs to treat patients using genomics, particularly those suffering from cancer and rare diseases. Other progressive institutions that have begun analyzing genes to determine what factors may provoke certain diseases. However, many of these projects exist

individually throughout the autonomous regions of Spain. The country still lacks unified national projects, which are key in establishing the relevance of genomics. It is time for health authorities to react to the changing environment. PPM is like a moving train that we need to jump onto, if we hesitate for too long we might lose our opportunity.

I like very much the French genomic plan because not only does it take into account the impact on healthcare, but also the impact on industry. PPM will lead the medicine industry into growth and prosperity resulting in job creation and societal benefits. I would like to see this same spirit established here within Spain.

What has the Roche Institute Foundation done in order to further introduce Personalized Precision Medicine into the current healthcare system?

While some projects are built from the top down, we believe the best way for a program like PPM to be handled is from the ground up. We are trying to jump-start the training in various areas – not only by working with clinicians but to also permeate the academic environment. To successfully do this, the concepts of genomics must be introduced as early as the university level. It is not a highly covered topic currently, but we are trying to change this and have created a genomics chair position at the Autonomous University of Madrid. Last year we developed a three-day course related to genomics for undergraduate university students in which students could earn credit towards their degree. This is a movement that must come from the universities, from the beginning forward. When the next generation of clinical professionals begin their practice, these ideas will have already been embedded into their rationale.

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What are the barriers of entry being faced by genomics in Spain?

The first barrier that Personalized Precision Medicine faces in Spain is related to infrastructure. At the moment, there is not a secure network to support the concept of how important PPM is. Not all institutions have a department of Clinical Genetics, in fact, so far it doesn't exist as an official specialization. There is needed much work to change the mindset at all levels. The progression of genomics also faces financial barriers. Like all investments, the funding is needed up front. However in certain sense, this is a matter of reorganizing budgets and better allocating resources to the most important initiatives. The regulation of PPM also must be carefully addressed as it continues advancing. The Roche Institute Foundation is working to bring recommendations on how to govern new programs, distribute information, and protect patient data and rights.

What does the future of Personalized Precision Medicine look like in Spain?

The Roche Institute Foundation vision for 2020 is to have brought the medicine of the future into the present. By developing a strategic national plan that will help stabilize the process of integrating genomics into healthcare throughout the regions of Spain, we could reach that goal. We will continue to focus from different angles, from legal to clinical, to spread information and awareness to all stakeholders from politicians to the patients and society. The key to progress is the diffusion of knowledge and the removal any stigma or doubt that may exist about PPM.

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