Tony Zbeidy, General Manager MENA, Recordati Rare Diseases

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The general manager for Recordati Rare Diseases in MENA, Tony Zbeidy, explains why awareness of rare disorders has vastly improved in the region, which has one of the largest incidence rates in the world, the particular importance of the Saudi Arabian market to Recordati, the need for a more collaborative scientific community, and the company's future plans.

Can you begin by briefly sharing your journey with the company and what drove you to devote almost two decades to rare diseases?

I joined Orphan Europe in 2003 at a time when it was owned by a Swedish businessman, one whom I respect greatly, who turned it into a multinational company. Orphan Europe was acquired by the Recordati Group over a 2 year period 2007-2009 and, following the deal, the company's name eventually changed to Recordati Rare Diseases.

My journey with the organization began as medical advisor and took a turn in 2006 when I was promoted to general manager for the Middle East and North Africa (MENA) region. Being a medical doctor by training, I was always fond of working in the rare disease space; it was a perfect match.

The rare diseases space has undergone a big transformation in the last 10-15 years, attracting attention and investment. What has your experience been from the inside?

The increased interest in rare diseases was brought about by a growing awareness around the subject, especially in the Middle East region where the consanguinity rate is considerably higher than in Europe or the United States. Saudi Arabia was a pioneer in the Gulf and Middle East, developing infrastructure such as at King Faisal Hospital in Riyadh which became the reference center for the entire region. Qatar, the United Arab Emirates and the other Gulf countries followed and also developed great standards. Today, we can appreciate great progress that is benefiting the patient population.

Saudi Arabia, for example, started screening newborns for more than 16 rare disorders when European countries were doing it for three or four, despite that advanced infrastructure and scientific backgrounds they have.

From a scientific society perspective, the US has the Society for Inherited Metabolic Disorders (SIMD) and Europe has the reputed Scientific Society of Inborn Errors of Metabolism (SSIEM), whereas in MENA, despite the high incidence of those disorders, countries have not yet managed to put in place a scientific society to address the issue.

In 2004, we gathered as a group of physicians creating the Middle East Metabolic Group and its first two annual meetings were organized supported by Drs from Saudi Arabia, Qatar, Kuwait, Turkey and Lebanon, sponsored by Orphan Europe. By 2015, the group had grown to include 250 metabolic specialists from the MENA region and Recordati Rare Disease devoted over EUR 300,000 yearly to the group. The group became mature enough to be transformed into an independent society representing 17 countries in MENA, the same SIMD represents US and SSIEM represents Europe. Various regional circumstances, including the Covid-19 pandemic, stalled our work, but we remain committed.

Naturally, it is not easy to bring together all the countries in the Middle East due to cultural and political differences. The region is a mix of culturally rich nations with varying degrees of financial capabilities. Within that context, Saudi Arabia has the privilege and advantage of being a rich country but also a country with a clear vision driven by its leaders; they want to diversify their economy, which is smart, but everything cannot be fully developed in one decades, it will probably take a couple of generations.

While countries in the Middle East have significant differences, they do share a high prevalence of rare disorders. How relevant is this topic in Saudi Arabia?

The Saudi authorities are very much aware of the need to support the rare disorder community due to the high incidence of these diseases. The country has a well-developed infrastructure to take care of children, however, the need remains to have a common effort supported by a regional platform and a dedicated budget to that effect. Saudi Arabia has the necessary capabilities to be a leader in this area. Today, the country has a well-developed infrastructure for metabolic rare disorders, for example, rare disorders are diagnosed and managed at maternity hospitals, King Faisal Specialty Hospitals, National Guard hospitals in the university hospitals and military hospitals in Riyadh, Jeddah and Dammam, many being established referral centers for rare metabolic disorders.

How big of an opportunity are metabolic rare disorders for Saudi Arabia to develop their scientific expertise and standing around the world, taking into consideration the high incidence and infrastructure you described?

There are no official figures, but I have estimated the incidence to be 11 to 13 times in MENA higher than in Europe or the US. Recordati is very much aware of the situation and is investing in scientific activities, organizing many regional workshops about Cystinosis, Homocystinuria, Hyperammonemia, Acute Porphyria, Acromegaly and Cushing’s syndrome, etc. The company is focused on raising awareness about rare diseases in the region and Saudi Arabia is a priority since it represents over 25 percent of the region’s economy.

Physicians are motivated by the workshops and meetings, participating as speakers. Collaboration will be key for the country because science is about exchanging information, building on knowledge and experience, and Saudi Arabia has the capacity to make it happen.

In my view, Middle Eastern countries are more used to doing it alone compared to European countries; my wish is that they collaborate more going forward because it will make all the difference for patients and children.

Clinical trials have been mentioned as an area of interest within Saudi Arabia’s Vision 2030, particularly for rare disorders. Does Recordati share their interest?

I have always pushed to involve the Middle East, and especially Saudi Arabia’s King Faisal Hospital and Research Center and National Guards Hospital in our clinical trials and studies. However, all stakeholders need to collaborate, including physicians and the people in charge of infrastructure. Recordati is very much open to developing greater collaboration with university hospitals in Saudi Arabia and the entire Gulf region to include them in multi-center trials.

Physicians are eager to collaborate, and we need politics to follow them; we need support from decision makers. As general manager for Recordati Rare Diseases in MENA, my goal is to help the patients to access life-saving medicine.

After 18 years of work in rare diseases for the organization, how would you describe the evolution of Recordati’s operations in the region and Saudi Arabia?

Prior to my arrival at Orphan Europe, the company had no presence at all in the Middle East; we established the subsidiary in 2006 with the opening of a subsidiary for Recordati Rare Diseases in Dubai.

Through the years, we have been building on that foundation, introducing our medicine to the markets, building teams, and creating partnerships.

In Saudi Arabia, our presence historically has been through partners, but, today, as Vision 2030 is encouraging companies to move regional headquarters to the country, we are evaluating possibilities to go beyond. Many companies have already established a direct presence in Saudi and Recordati understands that it must do so by 2024; fortunately, it is not either-or decision, we can expand our presence in the Kingdom while maintaining, or even increasing, our investment in other regional countries. Our organization appreciates the incentives being provided by the Saudi government to companies, including tax waivers, new ownership rules and fast-track approval processes.

What are the risks of switching to a direct presence and how is the company approaching that move?

All relevant business decisions carry risks. In Saudi Arabia, the circumstances appear to be favorable, but the pandemic has taught us that unforeseen events can change everything in a matter of days.

Saudi Arabia is an important market for Recordati Rare Diseases as it represents 25 percent of the MENA market. We are currently working through a vast network of distributors across the region, sharing medical information and reporting on pharmacovigilance. However, in the future we will need to have our own team in Saudi Arabia which could begin with a scientific office and grow step by step. There is a proverb that translates to “nobody can serve you better than yourself.”

Our long-standing company policy has been to expand and grow, and, as general manager, I am looking forward to making it happen.

To conclude, is there a particular message you would like to share with our audience?

Looking at the rare and orphan disorders field, we see that there is a special opportunity in the Gulf region because there is a large patient population waiting for solutions, which is very attractive for innovative companies that must go through the drug development process and sometimes struggle to find patients in Europe or the US. Our commitment remains to help patients regardless of their geographic location.

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