Ahmad Abu Dahab â?? Vice President Middle East, Turkey, and Northern Africa, Sobi

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Ahmad Abu Dahab became the first Middle East employee for Swedish-headquartered haematology, immunology and specialty care player Sobi back in 2012 and now serves as VP for the entire Middle East, Turkey, and Northern Africa region. Abu Dahab explains some of the key trends at play in the rare diseases space and how Sobi works in tandem with health authorities throughout his region to ensure that underserved patients can access the medicines they need.

Could you give us an overview of how you arrived in your position today and what your role encompasses?

I graduated as a pharmacist from the University of Jordan and also hold an MBA. I quickly commenced my career in the pharmaceutical industry, working at Novartis for two years before beginning my journey in rare diseases by moving to Genzyme in Jordan in 1999. This then evolved into a move to Saudi Arabia which opened doors as it is the country with the largest population in the region, so working for a rare diseases company gives opportunities to treat more patients. In 2012 I was offered and took up the role of employee number one for Sobi Middle East in Dubai/UAE. Now, I sit as the VP of Sobi Middle East, North Africa and Turkey.

I have been able to utilise all my experience gained from Genzyme where we went from one to eight products in the region. This mindset in building a company was crucial in setting up Sobi and if you look at the therapeutic area of rare diseases it has greatly evolved in the region. Prior to this, for Orphan/lifesaving medications there was no clear registration or reimbursement framework in place and this has all changed for the better today as patients have significantly better access to these life-changing innovative products.

How are Sobiâ??s regional operations run from your UAE offices and what are the key trends at play for the company within your region?

We have a fully-fledged organisation in the UAE offices that manages the operations for the entire region. This encompasses areas including medical activities to market access, regulatory, commercial, finance, compliance and supply chain.

As a company, we are dedicated specifically towards rare diseases and primarily to haematology. In 2016, we began our journey in this sector with the introduction of our haemophilia product, extended half-life Factor VIII and Factor IX, which kick-started our interaction with the payers, regulators, and the medical community.

Our goal is always to be able to deliver innovative medicines to patients as quickly as possible and our ability to do this varies across the region. For example, in Saudi Arabia, Qatar and the UAE we have never had to wait more than six months, in fact, these nations in many cases were the second markets to receive the products after the US. This exemplifies the governmentâ??s push towards promoting innovation and providing medical services equal if not better than what we see in Western countries.

In other countries market access is relatively slower, so we are working to initiate discussions with relevant regulatory bodies well before we even have a therapyâ??s approval, and more at the stage of positive clinical outcomes. This enables us to begin the process of enrolling patients and engaging in pricing discussions.

Nevertheless, I believe in the next five years we will see most regulators taking positive steps towards market access for our life-saving, innovative therapies. This is already happening in Turkey and Algeria where there is a window for patients to receive temporary reimbursement of therapies even if the medicines are not registered. This is crucial if there is no alternative medication, and the patients require this innovation to help change their lives.

What are Sobiâ??s most important markets in the region?

When it comes to lifesaving therapies, all markets are equally important, and our mandate is to ensure accessibility to all patients regardless of where they are. However, the common practice of identifying patients with rare diseases is more likely to be found in large populated countries.

This means that nations like Saudi Arabia, Algeria, and Turkey are strong strategic markets for us. On the flip side, smaller nations, like those found in the GCC, have smaller patient populations where hospitalsâ?? referral systems talk better with each other, so patient records show markers for rare disease patients faster.

Pricing negotiations are critical for market access. How do you achieve this when dealing with rare disease medications, which are generally more expensive?

Our strategy is to have early discussions with the relevant stakeholders even before the productâ??s launch. We create value not only for our patients and their families but also for governments when discussions are initiated to create awareness on the cost-benefit analysis and the value created to the overall nationsâ?? health and wellbeing. We look at health authorities as our partners in attaining sustainable healthy well-being as we bring our lifesaving products to the patients and the country in a sustainable manner is essential, and they are very receptive to our approach.

A big part of rare disease management is the interaction with groups to raise awareness of the conditions. How does Sobi go about interacting with these key stakeholders?

Each condition has its own awareness day, and this is driven forward by the community, be it patients, medical professionals, or the industry. For example, for haemophilia, we have an awareness period of nearly a month that focuses on all aspects: disease management, updates on innovative treatment, patientsâ?? education, family support and awareness. This also applies to other disease conditions. Coordination is done mostly at the healthcare authority level, and/or hospital level, so pharmacists, doctors and nurses all work diligently to make sure everything ticks over.

In regions like Europe, rare disease treatments have in many cases been given their own programs as placing them in normal reimbursement programs can put a strain on healthcare budgets. What is being done in the region you oversee to put in place such structures?

Western European countries such as Germany, France and Sweden have clear unified frameworks for orphan drug reimbursement for all residents. This allows faster identification, management, and equal access to treatment. In the Middle East, it differs from one country to another, and in the same country, there might be multiple reimbursement systems that patients may or may not access. One of the best practices in our region is in Saudi Arabia, where the Ministry of Health has taken the financial burden and set up programs to ensure better treatment access. However, this has substantially increased the budget being dedicated towards rare diseases in the country and caused pressure to expand the service to other rare diseases.

In terms of regional structures, we could learn from Europe which has a pan-European registry in place for many rare diseases. In the Middle East, it is a country-based system. If countries unite registry systems it would create more value to the healthcare community level. This value has multilevel benefits as it will increase awareness of disease identification, management, and progression.

What do you see as your main challenge throughout the region?

I would emphasise the previous point, as having a unified reimbursement system on a country level will definitely positively impact patientsâ?? health and well-being. This will extend the benefit to encourage industry researchers to conduct more clinical trials in the region and elevate the research centresâ?? knowledge and expertise in rare diseases.

Looking ahead, where will we see Sobi within your region in the future?

Sobi is transforming the lives of people with rare and debilitating diseases. We are focused on haematology and immunology conditions. Our mandate is ensuring every eligible person living with rare and debilitating diseases within our disease areas is given the opportunity to benefit from our approved medicines.

Our main objective is to continue decreasing the time from product launch to the product being administered to patients.

To adhere to our mandate at Sobi; on the regional level, we will provide our services in each country and on the country level, to be present not only within the major hubs but across all hospitals and centres. We aspire to end the suffering of each patient and work with the healthcare community to ensure that no-one is left behind.

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