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Mohamed Abu Shawish of Japanese rare disease specialist Kyowa Kirin outlines how, by focusing on initiatives like genetic testing programs and facilitating treatment delivery to remote areas, the company ensures that rare disease patients in Saudi Arabia receive timely diagnoses and access to essential treatments. He also explains how the presence of a dedicated team of local experts allows Kyowa Kirin to actively engage with stakeholders and navigate the complexities of the Saudi Arabian market effectively. By investing in local capabilities, Abu Shawish feels that the company fosters stronger relationships and contributes to improving patient outcomes in the region.

The last time we spoke, you were just starting in this role. Since then, what have been the key highlights and any insights gained along the way?

So far, itâ??s been a truly rewarding experience. There have been two key highlights. First, I am proud of the progress weâ??ve made in increasing access to our treatments for patients suffering from rare diseases, impacting both children and adults. It has been incredibly motivating to see how our work directly improves lives.

Second, we have allocated greater resources in Saudi Arabia. This strategic move strengthens our ability to serve the Saudi market and foster an environment of continued support to the healthcare community and patients. Iâ??m excited to see the positive impact this will have on patients in Saudi

Arabia.

In our last interview, you mentioned the importance of better understanding the patient journey to improve access. Could you share any insights gained from this process?

Understanding the patient journey has been pivotal for us in ensuring effective patient support and intervention where needed. We identified various points along the journey where intervention could be beneficial. For instance, we focused on improving awareness and diagnostic capabilities for rare diseases through initiatives like genetic testing programs, which have ultimately led to greater diagnosis rates. With diagnostic partnerships, we primarily address patient needs on a case-by-case basis, collaborating with local suppliers for diagnostic tests, which is integral to ensuring timely and accurate diagnoses. Enhancing access to treatment centers was another priority, particularly in Saudi Arabia. We support this through collaborating with various stakeholders. Despite positive strides, we recognize challenges remain in ensuring that patients we serve receive the optimal intervention, given the nature of rare diseases.

Another bottleneck we identified in the patient journey was sustaining treatment post-diagnosis. This is partly caused by logistical hurdles, especially for patients in remote areas. To tackle this, weâ??ve partnered with local entities to facilitate treatment delivery and expedite follow-up testing, alleviating the need for patients to travel long distances, sometimes requiring flights, for treatment or testing.

We are actively developing strategies and implementing tailored solutions to address the specific needs of each healthcare system in the country. We also seek to continue building partnerships that will streamline the patient experience.

Could you elaborate on your experiences in the Saudi market and how do draw on them today?

My familiarity with the Saudi Arabian market began in 2017 and has grown steadily, providing me with valuable insights into the market landscape. Iâ??ve witnessed a remarkable transformation in Saudi Arabia, characterized by a positive shift in mindset and continual enhancements in healthcare capabilities. Notably, renowned centers of excellence have played a pivotal role in elevating the standard of healthcare. This robust infrastructure created a strong foundation for us to support comprehensive care to patients.

We have witnessed excellent initiatives that have further advanced healthcare in Saudi Arabia, such as the transition towards a value-based healthcare system, where Health Technology Assessment (HTA) plays a key role in the drug reimbursement decision-making process, including the development of the first National Multi-Criteria Decision Analysis Framework.

In addition to this, Saudi Arabiaâ??s regulatory environment has undergone significant transformation and witnessed further improvement in terms of efficiency and alignment. This has helped us ensure that our treatments remain available for patients that need them.

When discussing rare diseases in Saudi Arabia and the broader region, itâ??s often noted that remote areas may exhibit higher prevalence rates due to factors such as genetic aspects. Could you elaborate on the correlation between remote areas and the prevalence of rare

diseases within your portfolio?

Absolutely, weâ??ve observed a correlation between remote areas and a higher prevalence of certain rare diseases. However, we do not yet understand the underlying reason for this. We are currently supporting a 10 year XLH Registry in the GCC region, including KSA. The XLH registry initiative will generate a wealth of data to add value to the understanding of epidemiology in the region better.

This presents a unique challenge and opportunity. While some areas may face greater unmet needs, they also potentially have more patients who could benefit from our treatments. Kyowa Kirin is committed to improving access to treatment for patients that need them and weâ??re actively exploring solutions to better reach this population.

You mentioned experiencing an accelerated approval path for one of your medicines in Saudi Arabia, which typically entails the need for real-world evidence to follow. Could you elaborate on the process and requirements for post-approval data generation and its impact on reimbursement schemes?

This is a crucial aspect to consider. Rare disease medications often address conditions with limited treatment options and a small patient population, leading to a lower number of participants in initial clinical trials.

To address these gaps, we aim to support local studies. We also advocate for post-marketing data generation by highlighting the unmet medical needs. Our medical team is actively engaged in supporting local data generation efforts. We believe this data is crucial in shaping future reimbursement schemes and ensuring comprehensive patient care for those living with rare diseases.

Beyond clinical trials, our global and regional EMEA Health Economics teams are constantly looking at measuring quality of life outcomes not only for patients, but caregivers too.

In some regions, patient communities are actively involved in regulatory discussions and societal alignment regarding rare diseases. Is there a similar community development around the disease areas you treat in Saudi Arabia, or is it still fragmented?

We have observed the emergence of patient societies in the GCC, which is a positive development. While in Saudi Arabia, whilst there is progress, communication among patients remains limited. With over 6,000 rare diseases, each presenting unique challenges, there are difficulties and barriers in attempting to unite everyone under one umbrella.

Encouragingly, we are seeing that patients are becoming more vocal through social media and feeling more empowered during discussions with their healthcare providers and caregivers. This year, we also supported various meaningful Rare Disease Day activities which brought rare disease patients and caregivers together in Saudi Arabia. We hope to see the establishment of stronger patient associations and support groups in the future, given the significant population within the region.

Are your products exempt from the arduous procurement process due to their unique nature in addressing specific unmet needs, or do they still have to undergo the standard tender process?

The unique nature of orphan drugs is recognized in Saudi Arabia. There are ongoing efforts to facilitate access to these medications that can significantly improve the quality of life for patients with rare diseases and their families. Weâ??ve observed a growing appreciation for the long-term benefits these drugs offer, and orphan drugs may benefit from an expedited regulatory pathway compared to more common medications.

It seems that your medical communication strategy requires a nuanced approach, especially given the rarity of the diseases you address. Can you elaborate on the challenges you face in reaching out to clinicians who may not be familiar with these conditions and how you tailor your communication efforts to meet their needs?

Absolutely, our medical communication strategy requires a multi-faceted approach due to the rarity of the diseases we address. HCPs may have limited exposure to these conditions, leading to challenges in diagnosis and treatment- this means many patients often have a long journey to an accurate diagnosis, some up to 7-10 years.

To address this, weâ??ve developed a multi-tiered communication strategy that leverages segmentation. We first identify which HCPs require support, such as primary care physicians who may be the first point of contact for patients. For these practitioners, we focus on creating awareness highlighting potential red flags.

For specialists who may already have familiarity with the condition, we provide more in-depth clinical data and treatment guidelines. By tailoring our communication efforts to specific needs of each audience, we aim to improve knowledge, diagnosis rates, and ultimately, patient outcomes.

Many might not be aware that Kyowa Kirin was the first biotech company in Japan. How important is awareness-raising of the companyâ??s status and history in terms of recruitment and ultimately patient impact?

Our significant heritage in Japan fuels our commitment to continuous innovation. This rich history translates into a wealth of experience and expertise that benefits both our team and the patients we serve, and it also means we look to the future with a long-term vision for generations to come.

As awareness of Kyowa Kirinâ??s scientific capabilities and positive impact on patient care has grown in the GCC, weâ??ve witnessed two key benefits. Firstly, we attract highly motivated individuals who share our passion for making a difference. This allows us to build a strong talent pool dedicated to overcoming barriers, or KABEGOE as we call it in Japanese. Secondly, a higher profile translates into increased access to collaboration opportunities, ultimately benefiting patients. This increased awareness can be attributed to the high-quality interactions weâ??ve had with key stakeholders in the market, as well as the tangible impact weâ??ve made on patient care.

Moreover, with the recent acquisition of Orchard Therapeutics, our focus on addressing high unmet medical needs, particularly through cell and gene therapy, is set to expand even further.

Looking ahead, Kyowa Kirin remains dedicated to leveraging its legacy and expertise to improve lives in the GCC and beyond.

Have you observed any changes in your operations due to having capabilities based in the country?

Weâ??ve established a strong team of local experts who possess a deep understanding of the market dynamics, regulatory landscape, and the specific healthcare needs of the country. This in-depth knowledge proves invaluable in navigating the complexities we may face.

The presence of this dedicated team allows us to be more than just present in Saudi Arabia; it allows us to be actively engaged. We are better equipped to address the evolving needs of the healthcare system and the specific requirements for rare disease patients. This fosters stronger relationships with all stakeholders and ultimately translates into smoother operational experience.

By investing in local capabilities, we demonstrate our long-term commitment to the Saudi Arabian market and our dedication to improving patient outcomes in the region.

Can you discuss how Kyowa Kirinâ??s vision aligns with Saudi Arabiaâ??s focus on healthcare and how the company aims to contribute to this vision, especially considering its own Vision 2030?

Saudi Arabiaâ??s Vision 2030 places strong emphasis on healthcare transformation, and I am excited by the many ways in which our Kyowa Kirin vision aligns with these goals.

Kyowa Kirinâ??s focus on innovative treatments for unmet medical needs directly translates to improving patient outcomes in the country. Among the goals of Saudi Arabiaâ??s 2030 Vision are increased access to quality healthcare, focus on innovation and building a knowledge-based healthcare economy. Our team focuses on delivering life-changing value, collaboration, knowledge transfer, supporting local data generation and investing in local talent.

Do you have any specific goals or objectives you hope to achieve in 2024 to maintain the positive momentum?

Looking ahead to the rest of 2024, weâ??re committed to building on our positive momentum. Our primary focus areas include reaching more patients, forging greater partnerships, particularly with the Ministry of Health, and ensuring that patients in remote areas are not overlooked.

Overall, I am incredibly proud of the progress weâ??ve made in supporting patient care in Saudi Arabia. By maintaining a collaborative approach and focusing on these key objectives, Iâ??m confident that we can achieve even greater things for rare disease patients in 2024 and beyond.

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