Diederik Kok – Head of GCC, Biogen

The most effective way to understand what is happening in the region is to engage directly with the ecosystem

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Biogen's transformation into a rare disease-focused organisation is reshaping how innovation reaches patients in the GCC. Diederik Kok, the company's GCC Head reflects on how global strategy translates into regional execution, from launching first-in-class therapies and navigating access for ultra-rare conditions, to building sustainable financing models, clinical research capacity, and genomic foundations for the future. The discussion offers a grounded, operational view of how urgency, evidence, and long-term planning converge in a region that is moving faster than many still realise.

How has Biogen's global strategic shift toward rare diseases translated into concrete priorities and ways of working in the GCC, and what have been the main challenges of executing that shift locally?

Christopher Viehbacher's arrival as CEO 3 years ago marked a clear inflection point for Biogen, with the strategic focus on rare diseases becoming tangible very quickly. That shift crystallised with the acquisition of Reata Pharmaceuticals in mid-2023, which brought Skyclarys™ (omaveloxolone), the first approved treatment for Friedreich's Ataxia, into our portfolio. From a regional perspective, this was not an abstract strategic move. The expectation was immediate and practical. Patients were waiting, and the organisation needed to be ready to act. For us in the GCC, that meant preparing to introduce an entirely new therapeutic area at speed, while ensuring the foundations were in place to support sustainable access.

The reality on the ground was that Friedreich’s Ataxia was clinically recognised but structurally invisible. Neurologists knew the condition from their training, yet years without treatment meant many patients had drifted out of care. Unlike markets such as France, where national registries provide clarity on patient numbers and referral pathways, the region lacked registries and reliable datasets. Awareness therefore became the primary challenge, not only among physicians, but also among patients who had long been told there were no therapeutic options. Addressing that gap required rebuilding visibility around the disease and re-engaging a clinical community that had little reason, historically, to actively search for these patients.

Our response focused on education and close regulatory collaboration. Even ahead of registration, the medical team worked with neurologists to deepen understanding of the disease biology, mechanism of action, and clinical evidence, followed by practical discussions on treatment integration after approval. In parallel, we engaged closely with the Saudi Food and Drug Authority (SFDA), where the orphan drug designation pathway allows priority review and earlier dialogue for therapies addressing high unmet need. In this case, that framework enabled approval within months rather than standard timelines, reflecting both the absence of existing treatments and the urgency for patients. At the same time, the limited presence of organised patient advocacy in the region means that healthcare professionals remain the primary conduit for awareness. Ensuring neurologists, nurses, and multidisciplinary teams understand that the treatment landscape has changed is therefore central to translating a global strategic shift into meaningful regional impact.

With recent launches in Friedreich’s Ataxia and SOD1-associated ALS, how have these introductions progressed, and what have they highlighted about access for ultra-rare conditions in the region?

We are now in the middle of the regional introduction phase. Regulatory approvals are in place across Saudi Arabia and the wider Gulf, and the focus has shifted to access and reimbursement. For SOD1-associated amyotrophic lateral sclerosis, this means working with an extremely small patient population, estimated at around 30 individuals across the despite a population of roughly 60 million. In Saudi Arabia, most diagnosed patients are concentrated in a limited number of specialised neurology centres, where expertise and active case finding are strongest. That concentration has been critical, as it allows rare patients to be identified, diagnosed, and managed more efficiently than would otherwise be possible.

Given the nature of ALS, timing is central. Clinical data show that treatment can delay disease progression, while untreated ALS advances rapidly and remains fatal. On that basis, several patients were treated ahead of full reimbursement through early access, or named-patient, mechanisms.. In Saudi Arabia, this approach aligns with the special access framework of the SFDA for unregistered medicines in serious, life-threatening conditions with no alternatives. In this instance, providing treatment while registration and reimbursement discussions continued reflected our view that early access was clinically appropriate and ethically necessary.

As access moves from early programs toward longer-term availability, how are you approaching sustainable financing and predictability for high-impact rare disease medicines?

As access evolves from urgency to sustainability, predictability becomes the defining challenge. One of the first steps for us was to engage with NUPCO, given its central role in national procurement and demand planning. A recurring issue in rare diseases is the absence of comprehensive national registries, which means that patient numbers are often unknown and budget impact difficult to anticipate. Our view is that this cannot be solved by any single stakeholder. Aligning data from the Ministry of Health, specialist hospitals, NUPCO, and companies such as Biogen allows a shared understanding of disease prevalence and creates a basis for more realistic forecasting. Even working from agreed planning assumptions can materially improve budgeting and reduce the risk of sudden, unplanned pressure on healthcare systems. This is already evident in discussions with King Faisal Specialist Hospital & Research Centre, where the core issue is not clinical value, but the fact that new, to be registered, rare disease therapies were not incorporated into annual budgets from the outset.

From there, the focus shifts to building evidence and policy frameworks that support longer-term decision-making. Much of our engagement with local payers centres on burden-of-disease and budget impact analyses, often conducted with independent partners, to translate clinical benefit into credible projections of demand and spend. In Saudi Arabia, this aligns well with the increasing use of health technology assessment, managed entry agreements, and real-world data to reduce uncertainty and support informed access decisions. Looking more broadly, some countries have addressed structural budget pressure through dedicated rare disease funds, particularly for paediatric populations, recognising that rare conditions require a different financing logic. Ultimately, sustainable access depends on better data, clear rare disease policies, and forward planning, so that governments can anticipate what is coming and make deliberate funding choices

rather than reacting under pressure.

How do you assess the GCC's positioning in rare diseases, and how are you preparing the ground for future launches across neurology and immunology?

The region remains under-recognised globally in the rare disease landscape, despite carrying a disproportionately high burden. Traditional market prioritisation tends to focus on the United States, followed by the largest European countries, and then markets such as Japan, China, and Brazil. That hierarchy does not translate well to rare diseases. In Saudi Arabia, and across the wider Middle East and North Africa, the prevalence of many rare and genetic conditions is higher, influenced in part by population structure and consanguinity. When absolute patient numbers are considered rather than conventional market labels, it becomes clear that the region likely represents a larger rare disease population than several European markets. A key task, therefore, is raising awareness at a global level so that development and launch strategies better reflect where patients are actually located.

At the same time, we are already laying the foundations for what comes next. Beyond neurology, this includes future programmes in immunology and genetically defined conditions, supported by partnerships such as those with Stoke Therapeutics and HI-Bio. This work starts well before registration. We are conducting clinical trials in the region and engaging more systematically with scientific leaders to build a clearer picture of patient populations, care pathways, and unmet need. The objective is to connect clinical development, regulatory dialogue, and reimbursement planning early, so that when data mature, the region is positioned to move smoothly from research into timely and sustainable patient access.

How is Biogen's clinical trial footprint evolving in the GCC, and how do clinical research and local evidence generation support sustainable access to innovation?

Biogen has built a credible and increasingly mature clinical trial presence in the region. In one programme conducted in Saudi Arabia, local centres ranked among the top enrolling countries globally, which was an important signal that the system can deliver when the right conditions are in place. That experience created confidence both internally and among investigators, and it has since translated into a broader expansion of activity, with additional trials underway in Saudi Arabia and growing engagement across other GCC markets. What is particularly encouraging is the shift in

momentum. Clinical research is no longer driven solely by industry interest. Health authorities, hospitals, and investigators in Saudi Arabia and the United Arab Emirates are actively seeking to host more trials, reflecting rising research capability, improving operational timelines, and a clear ambition to embed clinical research more firmly within national healthcare transformation agendas.

There is still work to do to compete consistently with long-established trial hubs in Europe, Japan, and elsewhere, particularly in terms of centre readiness and sustained investigator commitment. However, the region also has clear advantages, especially in rare diseases, where patient populations are often more concentrated and can be identified more efficiently. In Saudi Arabia, the role of the Saudi National Institute of Health, working closely with the Ministry of Health, has been particularly constructive. When patient identification proved challenging in one study, national stakeholders actively supported centres by coordinating efforts across regions rather than leaving individual sites to manage in isolation. This reflects a genuine willingness to work collaboratively with industry and a shared understanding that attracting trials also carries a responsibility to help ensure delivery.

The regulatory environment has further strengthened this proposition. Through the Breakthrough Medicines Program, the SFDA enables earlier engagement and, in selected cases, accelerated review for therapies addressing serious or life-threatening conditions with high unmet need. While not automatic, this pathway creates a realistic opportunity for Saudi Arabia to be among the earlier markets to register breakthrough medicines, rather than waiting for approvals elsewhere. For companies, this combination of clinical trial activity, regulatory flexibility, and early access makes the region increasingly attractive from a development and launch perspective.

Local evidence generation is the final link between clinical research and sustainable access. We are working with the Ministry of Health on programmes that extend beyond clinical trials to capture real-world data, particularly for high-cost rare disease medicines such as those used in spinal muscular atrophy. Within the managed entry agreement framework, outcomes are tracked once patients begin treatment, allowing reimbursement to be informed by real-world performance rather than international trial data alone. This approach supports more accurate forecasting, better budget management, and more confident access decisions, while ensuring that treatments are directed to patients most likely to benefit.

How can industry support the development of genomics and screening programmes in the GCC, and what is still needed to translate this progress into real-world impact?

Across the region, governments are making substantial investments in genomics, newborn screening, and broader health system infrastructure, and industry can add value primarily through knowledge sharing and practical experience. Screening programmes are well established in many countries, and there is scope to share lessons on how premarital and newborn screening can be implemented responsibly and effectively. Early identification is central to improving outcomes. In conditions such as spinal muscular atrophy, treatment initiated in the first months of life delivers markedly better results than later intervention. Industry can therefore work alongside governments and clinicians to help shape screening strategies that enable earlier diagnosis and treatment, while remaining mindful of the ethical and social sensitivities that accompany these programmes.

The region’s genomics initiatives already provide a strong foundation for this work. National efforts such as the Qatar Genome Program and the Emirati Genome Program are generating population-scale data that support earlier diagnosis, improved understanding of inherited conditions, and the longer-term development of precision medicine. What is now needed is faster translation from data to action. That requires closer collaboration between hospital-based scientists, academic leaders, and industry research teams, ideally through focused working groups centred on specific diseases. By combining complementary expertise, the region can move beyond data generation toward practical outcomes, ensuring that its growing genomic assets deliver tangible and lasting benefit for patients.

How has Biogen articulated its strategic transformation in the GCC, and how is this reflected in the region’s evolving portfolio?

As Biogen’s global strategy has evolved, a central focus in the GCC has been to communicate that shift with clarity and credibility. The emphasis has been on building awareness rather than promotion, ensuring that stakeholders understand both the science and the patient needs driving Biogen’s priorities. A clear example was a public Alzheimer’s awareness initiative in Dubai, which used cinemas as an accessible, everyday setting to reach a broad audience. The aim was to help people recognise early signs of cognitive change and encourage timely medical consultation, using simple, non-alarming messages that normalised the conversation and avoided fear-based communication. This approach has helped align external perception with Biogen’s renewed focus and reinforced a patient-centred narrative.

At the same time, the regional portfolio reflects both continuity and expansion. Multiple sclerosis remains a core area, complemented by spinal muscular atrophy, which has been part of the local

portfolio for seven to eight years and continues to see sustained investment, including the planned introduction of a new therapy in the near term. Beyond these foundations, Biogen’s neurology portfolio has broadened significantly to include treatments for Friedreich’s Ataxia, SOD1-associated ALS, and Alzheimer’s disease. In practical terms, this evolution largely involves the same clinical community. While neurologists may subspecialise, many manage patients across several neurological conditions, which supports long-term scientific partnerships and consistent engagement across disease areas.

When stakeholders ask who Biogen is today, the answer is rooted in that continuity of purpose. We present ourselves as a rare disease-focused organisation bringing advanced science to areas of high unmet need, built on a long track record of innovation in neurology. From early breakthroughs in multiple sclerosis, to first-in-class therapies in spinal muscular atrophy, the first approved treatment for Friedreich’s ataxia, and early leadership in disease-modifying approaches for Alzheimer’s disease, this history underpins a clear and credible positioning. It is the story of an organisation that has repeatedly helped reshape standards of care and is continuing that trajectory as its portfolio evolves.

How has Biogen evolved internally in the GCC, and what organisational priorities have shaped this shift?

As Biogen’s portfolio and ambitions have expanded, the internal focus in the GCC has been on remaining agile while operating at greater scale. A key change has been broadening engagement beyond treating physicians to reflect how rare diseases are managed in practice. Multidisciplinary teams, including nurses and physiotherapists, play a critical role in patient outcomes, particularly in neuromuscular and paediatric conditions where treatment extends far beyond the medicine itself. Strengthening education and scientific exchange across this wider care team has therefore become an important part of how we think about impact, alongside continued focus on the physicians who anchor care pathways.

At the same time, we have strengthened capabilities around value, access, and execution. This has meant building closer, more structured engagement with payers to articulate clinical and economic value, support formulary discussions, and ensure supply is aligned with real patient need. Internally, the emphasis has not been on restructuring, but on reallocating resources toward the therapeutic areas and stakeholders that matter most as the portfolio evolves. This approach has been further shaped by system reforms in Saudi Arabia, where healthcare delivery is increasingly

organised around health clusters. That model requires more targeted engagement with local leadership and priority sites, and it has been encouraging to see clusters proactively seek deeper scientific dialogue, education, and support in clinical research and real-world evidence. Together, these dynamics have reinforced an internal operating model that is closely aligned with how the healthcare system itself is evolving.

What are your priorities over the next few years, and how do you see Biogen's trajectory in the GCC evolving?

The immediate priority remains execution. We are continuing the introduction of the SOD1-associated ALS therapy and further advancing our spinal muscular atrophy franchise, both of which are central to delivering near-term patient impact. Looking further ahead, the outlook becomes increasingly compelling as Biogen's immunology pipeline matures. Between 2027 and 2029, several Phase III readouts are expected, with felzartamab, from the HI-Bio acquisition, standing out as a key programme in immune-mediated kidney diseases as well as Litifilimab in Lupus. Assets of this scale require preparation well in advance, which is why pre-launch work is already underway, spanning disease understanding, patient pathways, and early engagement with regulators to ensure that future access can be delivered efficiently and responsibly.

From an affiliate perspective, we expect continued growth, driven primarily by a steady increase in the number of patients on treatment. As we expand beyond neurology into immunology, this naturally brings new organisational requirements. Engaging additional specialties, including rheumatology and dermatology, means expanding teams and attracting new talent with the right expertise to support future launches. For an international audience, the message is simple. The region, particularly Saudi Arabia and the United Arab Emirates, is changing rapidly, often faster than external perceptions suggest. The most effective way to understand that momentum is to engage directly with the ecosystem, experience the pace of change first-hand, and become part of what is being built.

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