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Equity for rare disease patients is a question of prioritisation, not affordability.

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Dana Vigier, Regional Vice President at Alexion, AstraZeneca Rare Disease blends clinical training as a French general practitioner with broad pharmaceutical leadership experience. Formerly President of the French Pharma Association in Oncology and a Global Franchise leader at AstraZeneca, she now oversees Alexion's operations across Central and Northern Europe, including Switzerland, the Netherlands, the four Nordic countries, and Austria. In this role, Vigier has identified critical systemic inequities in rare disease access that transcend national wealth, advocating for fundamental reforms to healthcare frameworks and value assessment methodologies.

Could you begin by introducing yourself and your background, particularly how your clinical training influences your current role?

My perspective is fundamentally shaped by my dual experience as both a medical doctor and pharmaceutical executive. As a trained French general practitioner who worked in hospital settings before entering the pharmaceutical industry, I have a first hand understanding of the clinical challenges facing rare disease patients. This medical foundation has proven very precious as I have progressed through various companies and therapeutic areas, with particular expertise in oncology

development.

My journey included serving as President of the French Pharma Association in Oncology, which presented both challenging and rewarding opportunities to advance the field. At AstraZeneca I first looked after Oncology in France and then moved to overseeing a global commercial oncology franchise. For the past two years, I have been leading Alexion's Central and Northern European operations, encompassing Switzerland and a diverse portfolio of markets including the Netherlands, the Nordic countries, and Austria.

This regional scope has been particularly enlightening, as it has exposed me to the remarkable diversity of healthcare systems, regulatory approaches, and cultural perspectives across markets that are often inappropriately perceived as operating in a similar way.

What have been your most significant observations about the challenges facing rare disease patients across these diverse markets?

The most profound revelation has been the disconnect between national wealth and rare disease access. When transitioning from France, which receives substantial attention from Pharma companies as a large market, to smaller countries that typically receive less individual focus, I discovered a very significant diversity and unique challenges for each of these mid-size countries. .

My primary responsibility is to ensure that we maintain the same commitment to patient care at every point of care, regardless of the patients' geographic location. This requires deep engagement with local teams and stakeholders to understand the nuanced differences between markets that are often mistakenly viewed as homogeneous entities. For example, while we refer to "Nordic countries" as a collective, these four nations operate quite different healthcare systems with distinct cultures and patient-healthcare interaction patterns.

The strategic imperative is to establish proximity to local stakeholders—healthcare authorities, physicians, and patient advocacy groups—while developing comprehensive understanding of patient journeys that can vary dramatically across countries. Our objective is to ensure that innovation reaches every patient, whether they reside in Malmö, Graz, or in the Swiss Vaud canton.

How would you characterise Alexion's current position and strategic focus within the AstraZeneca portfolio?

Alexion represents thirty years of rare disease leadership, acquired by AstraZeneca in 2021 through a strategically astute approach that preserved Alexion’s internal autonomy. This structure maintains the agility and business flexibility essential for addressing the unique challenges of rare disease patients while leveraging AstraZeneca’s global infrastructure.

Our foundation includes twenty years of accumulated real-world data and evidence across our asset portfolio, encompassing seven approved therapies addressing eight different rare diseases. We have committed to delivering five new molecular entities to patients by 2030, spanning rare haematology, nephrology, neurology, and bone metabolism. Currently, all these therapeutic areas have Phase III trials in progress, demonstrating the breadth and depth of our development pipeline, probably one of the richest in the rare disease pharma industry.

Alexion pioneered the complement system approach, targeting a critical component of the immune cascade. When I was a young physician, the concept of addressing diseases like atypical haemolytic uremic syndrome or generalised myasthenia gravis through immune cascade modulation seemed revolutionary. This approach has proven not only correct but optimal, delivering the first innovation in myasthenia gravis treatment in sixty years.

The AstraZeneca acquisition has enabled significant global footprint expansion, addressing healthcare equity both within and across countries. We now operate in over seventy countries, while maximising R&D pipeline synergies, particularly in areas such as rare oncology and gene therapy where our combined expertise creates substantial value.

Could you elaborate on the rare disease landscape and the fundamental challenges affecting patient access?

The rare disease landscape encompasses over 7,000 distinct conditions, which collectively affect approximately 400 million patients globally. However, the rarity of individual diseases creates unique systemic challenges. By definition, rare diseases in Europe affect fewer than one in 2,000 patients, compared to hypertension at one in twenty or lung cancer at one in 1,000.

This rarity creates inherent discrimination within healthcare systems, not through deliberate intent but through structural inadequacy. Some general practitioners may encounter rare disease patients regularly, but for any specific condition, they might see no patients in their lifetime or perhaps two annually. This statistical reality makes diagnosis extraordinarily challenging, contributing to the average five-to-seven-year diagnostic journey.

The burden of rare diseases is approximately six times higher than common conditions, encompassing both financial and temporal costs. This burden includes the substantial healthcare consumption required to achieve accurate diagnosis, representing hidden costs within healthcare systems.

One of my most significant discoveries has been the complete disconnection between national GDP and rare disease access. Countries with exceptionally high GDPs do not necessarily provide superior access to rare disease innovations, revealing systematic bias that transcends economic capacity, while other countries with much lower GDPs have made rare disease treatment a priority.

Your research has revealed striking disparities in rare disease access across European markets. Could you share these findings?

The data is both compelling and concerning, when looking at drug accessibility data from the latest EFPIA W.A.I.T. indicator report for all therapies approved between 2019 and 2023, measuring the percentage of non-oncology orphan drugs accessible to patients by January 2025, the results reveal profound inequities that cannot be explained by economic factors alone.

Germany leads at 89 percent accessibility, while Italy achieves 76 percent. Switzerland, despite its economic strength, reaches only 59 percent. More strikingly, Bulgaria, with a GDP three times lower than Sweden, achieves 56 percent accessibility, while the Netherlands reaches only 45 percent, Sweden 29 percent, and Norway—with Europe’s highest GDP—merely 18 percent.

When comparing non oncology orphan drugs access to overall drug availability, the level of priority given to rare diseases in each country becomes quite visible. Germany maintains consistent performance across all therapeutic areas, while other markets show largely better overall drug accessibility when compared to orphan drugs. Switzerland’s overall drug availability rises to 73 percent, Sweden increases from 29 percent (for non oncology orphan drugs) to 50 percent, and Norway from 18 percent to 37 percent.

These findings are becoming acutely relevant also in the context of massive innovation coming in the area of rare diseases: over 50 percent of recently approved drugs by the FDA and EMA are rare disease treatments, representing the current wave of pharmaceutical innovation. This trend demands that healthcare systems urgently address their access and equity frameworks.

What factors contribute to these access disparities?

The primary issue is not affordability, as evidenced by Bulgaria's superior performance despite lower GDP for instance. Rather, it reflects policy choices and prioritisation decisions embedded within healthcare systems. Many systems utilise cost-effectiveness methodologies developed in the 1990s and 2000s, based on innovations like hypertension and diabetes treatments that involved trials with 10,000 patients: size matters when it comes to the methodologies used.

These methodologies are inappropriately applied to rare diseases, where Phase III trials typically include 50-100 patients, and ultra-rare disease studies may involve only 20 patients. The statistical frameworks designed for large patient populations cannot accommodate the inherent uncertainty associated with smaller study populations.

Additionally, systems with regional decision-making create geographic inequities within countries. While this approach may function adequately for common conditions with relatively uniform distribution of the disease, rare diseases may produce several patients in one region, while others will experience none over several years, creating treatment disparities based on the decision-making autonomy of each region when it comes to treatment decisions.

How receptive are stakeholders to addressing these systemic challenges?

Receptivity varies significantly across markets and depends heavily on individual stakeholder perspectives. Sweden for instance has demonstrated progress by establishing a new framework through TLV, their value assessment body, that better accommodates rare disease characteristics while maintaining cost-effectiveness principles. While potentially insufficient, this represents meaningful advancement and acknowledgment of the problem.

Other markets have shown limited recognition of these issues. Success ultimately depends on policy implementation by individuals, and people's perspectives vary considerably across systems and countries.

The challenge extends beyond health technology assessment to encompass financing mechanisms. We advocate for separating rare disease assessment and budgeting from general pharmaceutical evaluation, recognising that while rare disease drugs cost-effectiveness could be looked at and prioritized within a rare disease group and fund, they cannot be appropriately prioritised against therapies with large incidence and prevalence (allowing the use of standard assessment methodologies).

What role does Alexion play in addressing these access challenges?

Patient equity represents the core of our strategic approach. We operate through multi-stakeholder collaboration involving physicians, payers, pharmaceutical manufacturers, and patient advocacy groups. However, patients remain central to our decision-making process, consistent with Alexion's signature approach of comprehensive patient engagement.

We listen to patients in trial design, development planning, and strategic decision-making. This patient-centric approach extends to facilitating stakeholder dialogue. For example, our research indicates that 70 percent of respondents to a survey about "Understanding the experience of living with Generalised Myasthenia Gravis" in Denmark, Switzerland, and Austria, do not or rarely discuss the burden of gMG with their physicians.

We are implementing findings from these "bridge studies" across Switzerland, Austria, and other markets to facilitate better communication between patients and healthcare providers. These initiatives help patients articulate their individual needs more effectively while educating physicians about rare disease presentation patterns.

How do you view the role of patient advocacy groups in this ecosystem?

Patient advocacy groups represent crucial stakeholders whose voices must be amplified within healthcare systems. However, they require enhanced understanding of healthcare system mechanics, regulatory processes, and value assessment methodologies—knowledge not typically acquired through conventional education.

We serve as facilitators, creating platforms for mutual learning where advocacy groups gain system knowledge while healthcare providers develop better understanding of patient experiences and disease insights. This educational approach is essential because patient groups, while passionate and committed, often lack the systemic knowledge required to effectively advocate within complex healthcare frameworks.

The power ultimately resides with patients and their advocacy groups, but they must understand how to effectively leverage this power within existing systems. Our role is to provide platforms where the different societal stakeholders can meet and partner in order to improve patient journeys and experience.

What potential do you see for artificial intelligence in addressing rare disease challenges?

Artificial intelligence represents a transformative opportunity across multiple dimensions of rare disease management. AstraZeneca and Alexion are investing heavily in AI applications throughout our operations, from fundamental research through clinical application.

In research, AI addresses the challenge of developing treatments for conditions with no existing therapeutic precedents. Unlike common diseases where innovation builds incrementally on existing treatments, rare diseases often require completely novel approaches. AI accelerates target identification and compound development by analysing vast datasets and identifying patterns invisible to traditional research methodologies.

Patient identification for clinical trials represents another critical application. Finding rare disease patients for studies is extraordinarily challenging, particularly for early-stage disease research. AI tools can identify potential patients through electronic medical records, laboratory markers, and other digital health indicators, dramatically improving recruitment efficiency.

AI also enhances evidence generation by complementing traditional methodologies when patient populations are too small for conventional statistical analysis. This capability is particularly valuable given the limitations of conducting trials with 20-50 patients compared to thousands in common disease studies.

The ultimate promise lies in diagnostic acceleration. If we can reduce the diagnostic journey from five-to-seven years to one month, AI will likely play a central role in this transformation. However, this requires comprehensive stakeholder collaboration and willingness to reimagine traditional roles within healthcare systems.

What makes Switzerland particularly important for Alexion’s operations?

Switzerland hosts our European and international headquarters, encompassing all operations outside the US and Japan. This represents a substantial operational commitment, including my Central and Northern European team and our Swiss and Austrian local teams, creating a vibrant Alexion community alongside our AstraZeneca colleagues.

Switzerland offers a unique combination of stability and innovation. The stability encompasses employment, regulatory environment, and access to exceptionally well-trained talent. Simultaneously, the innovation ecosystem, particularly in the Zug area, provides access to cutting-edge technologies and collaborative opportunities that extend beyond pharmaceutical development.

Our strategic objective is to connect innovation dots across this ecosystem, leveraging Switzerland's technological capabilities to advance patient outcomes. The healthcare ecosystem is welcoming and collaborative, providing an excellent foundation for multi-stakeholder engagement.

What are your strategic priorities for Switzerland and the broader region over the next two to three years?

Switzerland has the potential to become one of Europe's leading rare disease healthcare systems, with the financial capacity to achieve this distinction. However, success depends on prioritisation and willingness rather than economic capability alone.

Our primary objective is advancing specific rare disease frameworks for value assessment and reimbursement, moving beyond Article 71 as the default mechanism. While Article 71 provides valuable interim access, it should not become the permanent funding route for rare diseases. The Swiss insurance-based system can create inequities where similar patients receive different treatment based on their insurer, undermining the principle of equitable access.

We advocate for clear recognition of rare disease specificities in assessment frameworks, particularly when comparators are sixty years old or non-existent. Additionally, we support independent national funding for patient advocacy groups, enabling them to maintain independence while strengthening their voice in healthcare policy discussions.

The broader regional objective involves helping stakeholders understand that rare diseases require separate frameworks for value assessment, patient organization support, and budget allocation. We view rare disease patients as a healthcare minority with unique needs, requiring specific protection against systemic discrimination.

This includes ring-fencing budgets specifically for rare diseases, establishing dedicated assessment frameworks, and ensuring equity across countries by minimising decision-maker proliferation. Every patient should receive equitable treatment regardless of geographic location within their country.

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