Johan Wäborg – General Manager Nordic Countries, Actelion



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General Manager Nordic countries at Actelion, shares the importance of Sweden for the group due to its world-class healthcare system and community of experts as well as its national quality and health registries which make the country an ideal environment for early launches and follow-up of treatment outcomes. He also talks about the synergies between Actelion and J&J which share the goal of improving the lives of people suffering from cardiopulmonary diseases through the introduction of improved diagnostic methods and new treatments.

Johan, you joined Actelion in Sweden back in 2006 and climbed through the ranks to become Business Director Sweden before taking on global responsibilities at the headquarters in Switzerland. In 2017, you came back to Sweden to head the Nordic countries. From this vantage point, could you tell us about the importance of Sweden for the group?

The Nordic region is one of the top seven markets in the EU for Actelion. As the largest country in the region with its 10.2 million inhabitants, Sweden is a very important part of the equation. In addition, Sweden boasts an excellent healthcare ecosystem with world-renowned university

hospitals and expert healthcare professionals who show a great willingness to collaborate with the industry to solve clinical challenges. In the area of Pulmonary Arterial Hypertension (PAH) in particular, the Swedish experts are respected globally, and the amount of publications coming from Swedish research teams and hospitals is above average in relation to the size of the country.

Moreover, two of the greatest assets of Swedish healthcare are the national quality registries and health registries that provide an unparalleled source of real-world evidence which will play an increasingly crucial role in drug development. The personal identification number enables linkage across databases on an individual level, a unique feature allowing the creation of unparalleled patient insight. Actelion leverages this incredible ecosystem through early launches of digital and R&D projects. Last but not least, Sweden has a thriving life science sector with a large talent pool to recruit from. Stockholm is the largest life science cluster in the Nordics, and the Oresund region – also called Medicon Valley – is not far behind.

What have been your strategic priorities since becoming General Manager for the Nordic countries?

As a company dedicated to fighting PAH, the priority has been to grow the awareness of this rare but serious disease and to make sure that all the patients get diagnosed early and receive treatment in one of the expert centres as soon as possible. However, we still have a long way to go before we reach our goal. In order to get there, we have to continue collaborating closely with the experts in the field and, I believe, we have to develop and introduce more effective diagnostic methods. Since the acquisition of Actelion by Johnson & Johnson in 2017, innovation in early diagnosis methods has accelerated with many interesting projects underway in partnership with medical technology companies. My anticipation is that Sweden and the Nordics will become first time users of these new diagnostic methods.

Moreover, while the legacy of Actelion is in PAH, our vision as part of Janssen is to create a normal life for people suffering from cardiopulmonary disease in general by expanding indications of our current products as well as developing new medicines and treatment regimen in combination with other drugs. For instance, Actelion is currently conducting Phase IIIb for a triple-combination therapy for newly diagnosed PAH patients. My priority is to prepare us for the introduction of these exciting new therapies and diagnostic methods, in collaboration with the community of experts.

Since 2007, Sweden has a national quality registry for PAH. How is Actelion leveraging this asset for product research and commercialization?

This national quality registry is a unique asset for the PAH community. At the moment, there are over 1,400 patients included in this registry, which is a lot relative to the size of the country and for a rare disease like PAH. Patients in Sweden are very open to sharing their health data. According to a survey commissioned by Forska!Sverige (Research!Sweden), 95 percent of Swedes are willing to share their health data. This creates an ideal situation to drive innovation forward and give patients access to better and more equal care.

Combining data from the disease registry with the healthcare databases allows us to build rich data sets describing the effects of disease and treatment on quality of life as well as the influence of socioeconomic factors in a way that is unique in the world. Actelion has been collaborating with and using the registry since it was started. For instance, data from the registry has been used to support product registration in other countries. In addition, ongoing global projects are building on extracts from this registry.

Moreover, Janssen has been collaborating with the Karolinska Institutet since 2015 in a number of different therapeutic areas. One of the aims of the collaboration is to study the relationship between data from randomized trials and observational data from clinical practice. Actelion can leverage the expertise in real-world evidence accumulated in this center of excellence in the area of cardiopulmonary disease.

Where does Sweden stand in terms of market access of orphan drugs compared to other countries in the region?

Historically, Sweden has been an early adopter of orphan drugs. In terms of market access, what sets Sweden apart is its value-based system of approval and reimbursement of new medicines. This value-based system allows a common central decision that makes it clear for doctors across the country what, how and when they should prescribe. Since we have been able to prove the value of our medicines compared to available treatment options, we have gained access sooner than in most other European countries.

However, due to Sweden’s regionalized healthcare system, national reimbursement decisions by the TLV do not guarantee uniform access throughout the country. How do

you navigate this complex regionalized system?

National decisions should give uniform access throughout the country, but in reality, there are differences. National registries make it possible to look at and correct these differences as a society. The people who work with the registries are committed to evening out the gaps and publish frequent reports. That is definitely one of the positive effects of having national quality registries.

While 26 European countries have already introduced a national plan for rare diseases, Sweden still does not have its own plan. How is the absence of a national plan affecting your reach?

It is rather strange that a country like Sweden does not have a national plan for rare diseases. In collaboration with patient groups, we have been advocating for a national plan for a long time. Nevertheless, as I said, Sweden has nevertheless been an early adopter of rare disease treatments. But it is always possible to do better. We should never be satisfied with what we have right now. Drawing some clear guidelines for financing, innovation and research would really help us achieve more. If we had a national plan for rare disease, I am sure Sweden could be a leader in the field.

What milestones would you like to achieve during your tenure?

I would like to shorten the time between the onset of disease to treatment initiation by three years so that patients can be treated earlier with our effective medicines. Today, the time from onset of disease to treatment is much too long, between three to five years. Our ambition is to completely take that time away.

Moreover, I am fully committed to the successful launch of Actelion’s future products in Sweden and the other Nordic countries.

You have been working for Actelion for over 13 years. What gets you out of bed in the morning?

The patients. Working in a rare disease like PAH is extremely stimulating because we can positively affect patients’ lives by working closely with the experts and other stakeholders. Ultimately, the goal is to cure the disease. J&J and Janssen have done it before. Back in the 1980s, HIV/AIDS used

to be a death sentence. Today, it is a manageable disease and patients can live a normal life. We want to do the same for PAH patients. A lot has happened in the past ten years in this small disease area. Looking forward, even more innovation will happen in the next ten years, especially in diagnosis, driven by Actelion and J&J.

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