Interview with Lis Callesen, Country Manager; Strategic Market Access & Public Affairs, Nordic, Baltic & Poland, Genzyme

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Usually the main issue when it comes to rare diseases is identifying patients. In Denmark we hear that because of the countryâ??s efficient social security system everyone is fairly well identified. Do you have the same challenges in raising awareness here as in other markets?

Awareness is always an issue because the patients we treat are rare. There are often times that a neurologist will not ever come across a Pompe patient or have the ability to diagnose another patient. On the other hand, due to the size of the country, it is much easier reaching to neurologists.

We do have a good system for children. I would say that all children are diagnosed quite early on because their symptoms are more obvious when it comes to rare diseases. But again, depending on how the disease progresses, it can take years before they are referred to the right department. The delay obviously causes many issues for patients. However, because Denmark is so well mapped, our public system makes it easier for us to get out into the clinics and work with the doctors. In additional, doctors are all seeking education, which is a good thing since it encourages access and openness when it comes to biotech. Coming from a biotech company, which has science and a patient focus as its main purpose, we see that physicians are very interested and open.

The treatmentsâ?? enzymes â?? are costly due to the clinical research cost the same as for other therapies. Development and manufacturing are expensive in biotech and the rarity of the disease meaning few patients to recieve treatment. Enzymes are biological products and it can take about 100 days to produce one batch of medication, meaning you can only make a little more than three batches per year. Itâ??s also due to manufacturing; mass production is impossible because the technology is very exclusive.

One element is to diagnose, and itâ??s another to be able to help and treat those that are diagnosed. In that area we have the exact same interest as doctors, patients, and clinicians and that is to be able to provide treatment because it makes a huge difference for patients; itâ??s literally a matter of life and death.

You mentioned earlier the fact that treatment is costly because of rarity. We are currently in a fiscally sensitive environment. How receptive is the Danish government to treating rare diseases?

They see it as a priority and in my belief they fully accept its equality as a treatment. As I say: if you think enzyme replacement therapy is costly, you should try the disease itself â?? because itâ??s much more expensive. Diseases really disable people, and not necessarily overnight. Disabilities can last 10 to 20 years so patients need all the help. For example, many Pompe patient cannot even breath. They need 24 hours of ventilation, which is costly because someone needs to provide care in the house at all times.

We can easily do the calculation for treatment costs. I always say that I can do it on the back of an envelope. With the proper treatment patients can have the ability to have a life. They can work if they receive proper treatment in due time, meaning they can pay taxes and again be an asset for society. They would also be able to take care of themselves, take care of their families and have a reasonable, normal life, which in the end makes treatment a huge investment for society.

In the bigger picture, rare disease treatment costs are not a significant amount of the governmentâ??s whole budget; some two percent of expenditures for medication are spent on rare diseases. So it is not a huge financial burden, but the clinical added value of orphan drugs is indeed accepted.

You mentioned that this is an exciting moment as a biotech company because the pipeline is very promising. Can you expand on what we can expect from Genzyme within the Nordic region?

We are very excited because we have a great pipeline. We are planning to launch new products this year and hoping to launch a full Multiple Sclerosis (MS) franchise, including an oral treatment. Although there are many products for MS, it is still largely an unmet medical need. MS fits right into our purpose of work, and we currently developing a therapy for first line treatment.

Genzyme is also hopefully coming with an IV formulation, which targets both the B and T cells and is completely new in the way it is administered. In the first year of treatment the patient will have five infusions over five consecutive days and then none for the rest of the year. The following year they will have three infusions over three consecutive days and, again, none for the remainder of the year. Currently between 70 to 80 percent of MS patients donâ??t require any more medication because their disease stabilizes. This is a completely new regime that has never been done before; it is absolutely promising. However, there are still so many people who are disabled from MS and we donâ??t know everything there is to know about the disease.

What will be the added value of Genzyme in a very crowded MS market?

The value comes back to our patient focus. We will bring the holistic approach to the patient because this is our expertise in rare diseases and enabling patients live normal lives. For example, if a patient is still traveling around the world for work or pleasure, they will still need to receive their necessary infusions. We provide for those arrangements. Seeing the whole patient is a fundamental component of Genzyme and we bring the same focus to MS.

We also know that with MS, actual medication encompasses just 10 percent of the disease. Other concerns are related to social life, family life, and career. So we are launching â??Spiritâ?•, which is a program for patients and healthcare professionals. Itâ??s about positive thinking and being able to evolve and get over chronic diseases so they do not affect your entire life. Itâ??s about how to be compliant with your life situation; how to get the most out of your life even if you have a serious diagnosis. We are just now launching the program and are out in the hospitals telling healthcare professionals about it. Patients and professionals can sign up online and those who want to take classes can do so online at their own pace. It is a holistic approach that they can follow.

How many products does Genzyme have in the Danish market?

We have four enzymes Cerezyme, Fabrazyme, Aldurazyme and Myozyme and two new MS products that are hopefully coming soon. We also have a portfolio in endocrinology and cardiology.

How has Genzyme experienced the acquisition by Sanofi?

Genzyme was founded in 1981 and started in Denmark in 2001. In 2011, Genzyme was acquired by Sanofi but we still maintain our separate brands. It was a good decision by Sanofi to keep Genzyme on its own biotech platform because itâ??s such a huge brand. Itâ??s a move seldom seen because an acquisition normally means that the purchaser will buy all the products and rename the company that they are taking over. But here they did the opposite; they really wanted Genzyme to stay as Genzyme and evolve the branding and its values because our values are patient-centric. Itâ??s not just something we say, itâ??s something we do. And thatâ??s the strongest reference you can show to someoneâ?? what you do.

No doubt Sanofi bought Genzyme for more than its products. Sanofi also bought Genzyme for the pioneer spirit, the culture, the values and all the research and development going on. They bought it for its entrepreneurial culture and its role as a value-based company. When I hire new employees, I very much go after their values. But they also need to have the right mindsetâ??to be entrepreneurial, to have that passion, to feel deeply for biotech science and what it can do for patients. I donâ??t want work to feel like a task, but rather, that you have a strong sense of purpose for doing what you do and that all employees have an important role to play. We are all very happy when we are able to help patients and health care professionals and a lot of my colleagues have a photo or a name of a patient that serves as daily inspiration.

Whenever we go to a Genzyme office anywhere in the world, there is always a strong sense of corporate culture. How do you explain the fact that everyone has the same passion to do the job well for the patient?

It is a passion for rare diseases for one, and an interest in the ways and means to treat patients through the products. It is a matter of life or death, which is a life changing experience. It does a lot to people who hear about these stories no matter where you are, and that is what biotech can do. I expect a lot from this company since we believe we can do it.

If we come back in five years for a follow-up report on Denmark, what will we find in Genzyme?

You will find us here. We will be successful in MS and we will be able to treat even more lysosomal disorders. There are over 40 types of lysosomal disorders and at the moment we can only treat four or five, but in the next five years we will be able to treat more. Genzyme is deeply involved in MS and we will also be involved in other areas, continuing to apply science to unmet medical needs. Lupus for example, is a rheumatology specialty with little treatment options. There are many patients who could really use the help. I expect Genzyme to take responsibility. If anyone is able to take the lead in this unmet medical area, Genzyme has to show the way. We have to take responsibility in science because we can, and if you can, you should. My mission at Genzyme is about the patients and the science that serves as the foundation to improving their lives.

Do you have one particular story that serves as a constant reminder of the impact Genzyme makes on the lives of patients?

There are countless touching stories. One of which is this particular Pompe patient who was seeking treatment. It took a little while for him to begin receiving treatment, which devastated his friends and family. His wife could see her husband gradually deteriorating and she was brought to tears. But, finally the patient started treatment. Gradually, the medication and treatment led to a significant improvement in his daily life. She told the treating physician hat they are now able to â??dance around the table.â?• Because of the medication and the treatment they were able to do a little something that they had always done before â?? dance around just a little bit, reminding them what a great life they have together.

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