

Foundations as Catalysts for Health-Related Projects

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Novo Nordisk is a Danish pharmaceutical company, specialised in diabetes since soon after the discovery of insulin in 1922, but also in haemostasis and growth hormone. It was formed by the fusion of Novo Pharmaceuticals and Nordisk Gentofte Pharmaceuticals in 1989 and currently ranks number 16 in the industry's tables. Both the individual companies and today's Novo Nordisk have a strong tradition in foundations for furthering medical and social aims. Nordisk Pharmaceuticals established the Nordisk Insulin Foundation (1926), while Novo established a specialised hospital for treating diabetics (1932). Novo Nordisk created the Novo Nordisk Foundation (1989), the Steno Institute, a foundation dedicated to basic diabetes research (1992) and, almost a decade later, the World Diabetes Foundation, to take diagnosis and care programmes into the developing world (2001).

The Novo Nordisk Haemophilia Foundation (NNHF) was established in Zurich, Switzerland, in 2005, with the vision of ensuring adequate care and treatment for patients with haemophilia and related bleeding disorders. Haemophilia is an uncommon disease but is nevertheless familiar to many as the "Royal Disease", the hereditary bleeding disorder that ran through the noble houses of Europe. It is mentioned in religious texts several thousands of years old. The inability of the blood to clot properly and the extensive bleeding into the joints, muscles and soft tissue, is due to a lack of the circulating clotting factors, VIII or IX. The genes for these factors are carried on the X-chromosome with the result that only male offspring clinically manifest haemophilia, although females can be carriers. The British Queen, Victoria, was herself a carrier and transmitted haemophilia into the lines of Hesse, Prussia, Waldeck, Cambridge, and Battenberg, and thence into the royal house of Spain. Probably the most renowned of the haemophiliacs stemming from Queen Victoria is the Russian Prince Alexei Nikolaevich who died at the age of 16.

Treatment of haemophilia today is routine and is accomplished by regular intravenous infusion of one or the other missing factor. In the developed world, these clotting proteins are now available from recombinant technology which renders them essentially safe from the transmission of virus diseases, thus overcoming the serious drawback of early preparations isolated from human plasma which transmitted hepatitis B and C, and HIV, in the 1960s to 1980s. Treated haemo-

philiacs now have a life expectancy approaching that of normal persons and the cost of lifetime substitution of factor is offset by the fact that the socially assimilated, mobile patients can work and contribute taxes.

In contrast, the situation for haemophiliacs in the developing world is not so rosy: There is a general lack of knowledge and awareness about the disease among patients and healthcare specialists alike; cultural taboos prevent parents presenting their afflicted children; there is a lack of diagnosis due to insufficient laboratory capacity and screening programmes, etc.; for many national governments, haemophilia is not a healthcare priority in the face of other mass health issues, such as malnutrition, malaria, HIV, tuberculosis, etc. An estimated potential 400,000 patients in the developing world receive no treatment, or inadequate treatment, and they die at an early age.

Against this background, the NNHF was created to improve the infrastructure to deliver healthcare solutions for haemophilia in the developing world. Sponsored by Novo Nordisk, this independent, non-commercial foundation under Swiss Law has an annual income of about CHF 2 million, a Council and a management staff of three. It operates in those developing countries defined by the OECD Development Assistance Committee (DAC) list as low, lower middle and upper middle income, as well as the so-called "transition" countries, those which have recently joined the EU or are shortly intending to. As a general rule, and because it does not have the resources, NNHF does not work in the Least Developed Countries. These have little infrastructure, such as blood transfusion services or patient groups, on which to base projects, as well as different healthcare priorities. Within this list of countries, NNHF tries to maintain a selective strategy of working in countries with emerging economies, for two reasons. As the standard of healthcare improves with increasing economic prosperity, so does the capacity of healthcare systems increase to cope with marginal diseases, such as haemophilia. At the same time, patient expectations of benefiting from better healthcare rise.

The activities that NNHF performs fall into three main categories. These are: Capacity building, which is nearly always educational in nature, such as physician training and patient education; Awareness creation which includes diagnostic programmes, establishing

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laboratories and training staff to run them, and creating patient registries for statistical disease evaluation; Reduction of disease impact, which translates into preventing the complications of untreated haemophilia, such as chronic joint destruction and muscular atrophy. These activities are carried out as managed projects lasting for periods of one to three years with financial values of between CHF 50,000 and CHF 500,000.

In the space of its almost three years of existence, NNHF has a project portfolio of 22 projects in 20 countries worldwide, with a total award value of CHF 4.4 million.

The advantages that foundations enjoy over national organisations and governments in the developing countries in which they work are the ability to work in a concentrated but flexible manner for defined, limited periods of time against measured targets set by consensus with the beneficiary. This defines their role as catalysts in being able to create highly effective, highly visible change in healthcare systems within a short time.

But also for foundations, the rules of engagement are changing. A new generation of stakeholders has emerged desiring more direct "hands on" involvement or accountability in return for its sponsorship. This has led to an increase in the use of project management methods to achieve structured progress and payment to beneficiaries based on results, so-called "results-based performance". Sponsors are moreover interested that their funding yields permanent or sustained improvement in healthcare. Sustainability has become a key start criterium or deliverable and requires that governments in project countries assume their full responsibility for improved healthcare at project end. Lastly, most healthcare problems are financially intractable to all but the largest foundations. This makes the engagement of third party stakeholders and private individuals as additional contributors with leveraged money, in kind or with moral support essential.

In summary, foundations like the NNHF can fulfil a unique role in initiating healthcare improvement in areas unaddressed by governments or society. In the developing world, this is typified by their engagement in mass and major diseases for which resources or infrastructure are lacking, as well as in marginal diseases such as haemophilia.

Looking back, foundations have been successfully and traditionally engaged in areas such as medical research, medical education and care, and the establishment of general and specialised hospitals, operations and more. This long-standing engagement will continue as long as there are healthcare challenges in the developing world to be solved.