This man has multiple sclerosis and seeks after a cure. How the American Scott Johnson - along with the Hertie Foundation - changes the discovery process.
The Hertie Foundation cooperates with the Myelin Repair Foundation – and builds a bridge to Europe according to a new principle of medical research.

Twelve years ago the physician and scientist Robert Miller approved an experiment that today may change all of medical research. In 2002 Miller sat in his office at Case Western Reserve University and listened to what Scott Johnson, the man in the chair opposite his, was telling him: He had founded a foundation, the “Myelin Repair Foundation” (MRF) where he wanted to develop drugs against multiple sclerosis – with an unconventional approach. The foundation did not want to perform research like an academic operation, but more like a company, with result-oriented cooperation and clear goals and deadlines. This sounded good in theory, but did not sound promising to Miller in reality. He almost did not participate. Scientists want to acquire a reputation and publish in professional journals – how would this be possible if they accepted a subordinate role in a team and, due to the agreed on goals, conducted research in areas where there were no prospective high-ranking publications? This man is no physician, Miller thought, he has no idea what goes on in academic life. Miller thought about it and still agreed. “It was an experiment and scientists are interested in experiments,” Miller says today. And as there were more and more successes, he slowly realized that the outside impulses were the key: someone simply went beyond the outdated barriers that academia had imposed on research scientists for decades. Now the Hertie Foundation and the Myelin Repair Foundation want to bring this new way of conducting research from the USA to Europe together.

The Patients Above All

Eva Koch of the Hertie Foundation has been responsible for the foundation’s multiple sclerosis research for eleven years. She met Scott Johnson in 2010 at a conference in Berlin. “When I heard his lecture I knew that he wanted to make basic changes,” said Koch who had...
already focused on multiple sclerosis when she was a physician and not a project manager with the Hertie Foundation. Multiple sclerosis is the most common inflammatory disease of the central nervous system worldwide; in Germany alone there are 130,000 patients, most of the time the disease starts in early adulthood. In chronic multiple sclerosis the sheathing of the nerve fibers in the brain and spinal cord – the so-called myelin sheaths – are attacked and destroyed by the body’s own defense cells. The consequences: vision problems, paralyses, episodes of multiple sclerosis can basically cause almost any neurological disorder.

The etiology is unknown. But Scott Johnson does not just want to understand the disease – he primarily wants to treat it. And help the patients as quickly as possible. This is the ultimate goal. But the research goal is often not as direct as drug development – even if this might be suspected as a layman. The MRF and Hertie Foundation want to change this and put the focus of the research on drug development.

**Skeptical Enthusiasm**

Scott Johnson, 58, has a friendly face with alert eyes. He is sitting in his office at the MRF headquarters in Silicon Valley, San Francisco Bay area, and looks into the computer camera. “Yeah, it was not that easy in the beginning,” he says and smiles. The research scientists were skeptical. “They were all enthusiastic about the idea of conducting research this way with the result being something useful. But most of them did not believe that this would actually work,” says Johnson. This was also due to them being wary of the prospect of working together more closely with the pharmaceutical industry. Their experience was that the pharmaceutical industry initially does not pay attention to many results for a long period of time. The reason: it is insufficient for the drug developers if, for example, the efficacy of a certain substance was only proven once and published – this is often an isolated, almost coincidental effect that can not be repeated regularly. Roughly only every tenth proven result can be repeated reliably under industrial conditions – to the pharmaceutical industry further experiments thus only make sense if repeated efficacy has already been proven. Research scientists, however, rarely try to confirm results already detected, because information that is already known can of course be no longer published in high-ranking journals.

“We are building a bridge across the ‘translational gap’.”

There has thus been a gap between pharmaceutical companies and academic research for some time: much knowledge gained during basic research disappears without being utilized in drug research and thus be applied. The Myelin Repair Foundation closes this gap known as “translational gap” in terminology with its own laboratory where attempts are made to repeat promising results according to industrial standards. “A bridge is being built across this gap this way and through the increased exchange of information between the pharmaceutical industry and academic scientists,” according to Eva Koch of the Hertie Foundation.

**Fast Development of Drugs**

Furthermore, many research scientists such as Robert Miller were initially worried that they would publish less and lose importance and influence in the field. It was only shown in the course of years that the MRF scientists were able to publish even more as a team. “We are aware of the results of our studies among ourselves – for years before they are published. This gives us an enormous advance in knowledge,” Miller explains. And through being in contact with the pharmaceutical companies’ research scientists, who the MRF brought together, Miller and his colleagues are more aware of what is important for knowledge to quickly turn into a clinical application from which the affected patients will profit.
Fast development of new drugs. This is what Scott Johnson wanted from the beginning. He himself developed multiple sclerosis in his early 20s. Johnson was not familiar with the field of medicine at that time; he wanted to become an engineer. It wasn’t until after successfully managing several startups – far from the field of medicine, in technology and other industries – that he started to deal with the disease more in his late 40s after having had multiple sclerosis for almost 25 years. “I realized that the goal of almost all therapeutic approaches was suppression of the immune system. This method makes sense. But there are other possibilities to treat the disease. And those were neglected,” says Johnson. He founded the Myelin Repair Foundation that specializes in researching myelin sheaths in which the neural pathways are embedded and which are attacked by the immune cells in multiple sclerosis. The foundation’s goal is to develop drugs that can repair these myelin sheaths and protect them.

“We set a goal of placing a drug to repair the myelin sheaths in the clinical phase of development within fifteen years; this normally takes 30 to 50 years,” according to Johnson. For this reason, research scientists all over the US meet for a virtual conference on the internet once a month, and in person three to four times a year, to exchange information on the progress made and to help each other with problems. Physicians and molecular biologists of pharmaceutical companies often participate and consistently explain to the research scientists under which conditions they will start their own research and try to develop a drug.

“I ultimately want this disease treated. That was always my motivation.”

“When I heard this for the first time, warning bells went off. After all, we as a foundation don’t want to do the pharmaceutical industry’s work,” Eva Koch explained. But this is not the case: the cooperation with the pharmaceutical industry only serves to close the aforementioned “translational gap” – afterwards the drug manufacturers generally take over and they alone carry the costs.

Something Completely New

With this cooperation, the two foundations are attempting to build a bridge to Europe for this new type of research – and to gain multiple sclerosis researchers for the project in Germany as well.

“We are known in Europe in multiple sclerosis research, for which reason most research scientists are very open when I approach them with the new idea,” according to Eva Koch. However, there is still repeatedly skepticism. Many view it like Robert Miller did in the beginning. “It’s not conventional science being conducted, but something completely new,” says Miller. A strict objective with deadlines and controlling, working together as a team where everyone has to keep his or her ego in check – all that does not have to be confined to myelin sheath research in multiple sclerosis, this could change all of medical research in case of prolonged success. Even if this requires patience, something Robert Miller is aware of: “Team conferences each month, reviewing the direction each time, whether it is consistent with the objectives, that takes some getting used it. It takes time.”

Three Active Ingredients Being Tested

But apparently it doesn’t take too long. Because the Myelin Repair Foundation achieved more in only ten years than Scott Johnson had hoped. The goal of achieving development of the first drug within 15 years remains on track: in the meantime three active agents the research of which was expedited by the Myelin Repair Foundation are being tested in clinical studies – and might be on their way to becoming drugs. More and more scientists have been working on myelin sheaths since 2005 – it is certainly possible that the activities of the MRF also contributed to this development. “In the meantime some prestigious universities and institutes started working on this. Of course, we don’t consider that competition, but very much welcome it,” says Scott Johnson.

Miller explains the success this way: “We have a very diverse team and if there’s confidence and spirit, the resources complement each other much better and new results and ideas develop faster."

Will Scott Johnson profit from all of this? “My goal is that the disease can finally be treated successfully. That was my motivation from the beginning,” says Johnson. Of course he hopes that he himself can profit from a drug that repairs the myelin sheaths. But he has had the disease for 38 years now, a long time during which a lot of damage was done to his nervous system. To him it is about the people who recently developed the disease or in who it has yet to develop. But he does not want to give up hope for himself entirely.