Preface

Doctors are used to obeying orders. Hardly another profession is so dominated by external regulations and knowledge that either cannot be disputed or only selectively, with a great deal of effort. From the beginning of their medical studies, future doctors are drilled to absorb this knowledge without criticism. Any other mind set would make it impossible to take in the reams of learning material. I experienced my own transformation and witnessed fellow students go through it too. I can remember how we were all in awe of our professors, I recall our conversations whose purpose was to check how hardworking, intelligent and insightful the others were. We competed in who could pore over the thickest books or read the most journals, who could fit in all the lectures or even make it to the congresses. But it was always other people who explained to us the way things worked. We just regurgitated it.

Many doctors stay in this mind set after their studies. They use information researched and compiled by others, like using a computer without understanding its inner workings. Chief physicians, who often treat their subordinates like stupid schoolboys, take the place of professors. Guidelines for almost every symptom, agreed upon by leading representatives in endlessly long meetings, take the place of textbooks. These guidelines are often compromise solutions in which well-founded opinions with no majority support are swept under the carpet. And besides this, doctors have to comply with ever-more complex requirements from health insurance and legislation bodies while being squeezed by economic constraints. They are susceptible to information that is cleverly circulated by pharmaceutical firms and presented by paid academics to tempt doctors into prescribing extravagant, ineffective treatments. On balance, however, many in the profession succeed – and this is not be underestimated – in giving sound medical treatment to the majority of their patients. This is because the system of thought in conventional Western medicine, accumulated over millenniums from jigsaw pieces of knowledge, is effective in treating many illnesses without the doctor having to understand the original cause of the illness. The established pattern of diagnosis and treatment generally makes sense.

Yet this system, on the other hand, allows little room for the art of medical practice – a term that seems outdated because it is so rarely used. This book is about medical artists. They do what artists do. They improvise, are led by their imagination and vision, trust their gut instincts more than logic or evidence, and create the medicine of the future without losing a grip on traditional knowledge of conventional medicine. Only some have chosen this role of their own accord. Others have been thrust into it because patients have led them to the frontiers of medicine where guidelines lose their significance. There, they are isolated, without a textbook or publication to show them the way. They have to do what doctors did centuries ago: that is, to devise treatments at the sickbed.

For many years, I have been seeking out these kinds of doctors and patients. Some are not difficult to find; they have already hit the front pages of the tabloids, such as the neonatologist who helped give birth to the “youngest premature baby in the world”. But media coverage in this case never went beyond the basic facts because the family shied away from publicity. Why, for example, did the doctor decide on maximum treatment, even though the baby’s statistical chances of survival stood at zero? How are the parents coping with their child now? Will she be disabled for life?

Other cases receive a great deal of attention within expert circles, and the doctors concerned are awarded the highest accolades for their innovations without the public ever knowing. Like the story of the thorax surgeon who invented the world’s first artificial air pipe in the laboratory together with his wife, a basic research scientist. But why did the surgeon perform the operation for the first time, despite having prepared it for years, on an Indian immigrant who no longer wanted to live and had swallowed oven cleaner? Did the Indian, who had to spend months in intensive care facing death, accept the gift of a second life?

I heard about one case through my circle of friends. It was the story of a doctor on emergency call who had to revive a person suffering from hypothermia whose core temperature had fallen to just 17 degrees. Was this person already dead or still alive? The manuals on emergency treatments didn’t offer any answers – the worst form of hypothermia started at 28 degrees. Was the doctor going to revive a zombie by performing reanimation?

Another case goes back to one of my own experiences in the department of neurology. The patient in question was suffering from a mystifying brain condition, and his state had visibly deteriorated over a few weeks. We carried out many examinations, sent samples to special laboratories and still couldn’t find anything. I was sure that he was suffering from an illness that we hadn’t yet discovered. The case stayed with me for a long time. Last year I spoke to many neurologists until I came across a young specialist at Berlin’s Charité who was researching a brain illness that had only just been discovered. It was curable if the patient received the right medication. I discussed my case with him – and received the belated reply:

yes, my patient had probably been suffering from this brain condition. But I could no longer locate him.

Through my interviews, I wanted to find out when and why doctors go beyond their limits and what part the patients have in these doctors’ decisions. Sometimes it was a key role, such as the woman who said to her doctor in the last stages of cancer: “I’m prepared to go through anything to give my children a mother for as long as possible.” The doctor felt compelled to carry out her request and imposed on her what he would ever only impose on himself: maximum treatment with full risk. What kind of woman made her doctor go so far?

To answer all these questions, I have reconstructed the stories very precisely, I have studied medical records and nursing charts, talked to close relatives, and phoned medical insurance companies who challenged courses of treatment and sought recourse against doctors.

I have met doctors who are very different from the majority of the medical profession. They suffer from the things that medicine is still not capable of doing. They recognise that our concepts of illness, diagnosis and treatment are not nearly sufficient and have to be developed, just like in the old days. They don’t shrug their shoulders and say: “We can do no more.” Instead, they do research and accrue files of specialist literature, driven by their quest to find the solution that might save a life. They are all united by a readiness to take unconventional routes, and accept criticism and malice if they fail. And they never give up. They have given their patients EVERYTHING. Sometimes, just in one isolated case when the situation and person required it of them.

I have met patients who have a hard fate with rare illnesses; I’ve witnessed how their life, and their relationship to partners and children, has transformed over the years. I have asked them for very detailed facts, which has sometimes led to me stumbling into situations that I was not able to deal with – when I felt more like a therapist than a journalist. But in the end, these people were happy to have talked, sometimes for the first time, about everything. From them I discovered what characteristics a patient must have for a doctor to go beyond his own limits – unshakeable resolve, a determination to take on the highest risks and the capacity for a basic sense of trust. Every patient in this book was prepared to put his fate in the hands of his doctor.

It enabled these patients to go on a journey with their doctors into the mysterious realm of unexplored medical treatment and unproven knowledge. The ends of these journeys were marked by milestones in medicine, some of which have entered the annals of recent medical history, but others were only known to a handful of people up until now. The case histories that I am going to talk about seem unique and spectacular. Yet every year, thousands of these kinds of untold stories take place, ones in which doctors surpass themselves – doctors who at least occasionally regard their profession as art.

DOCTORS – Chapter: Fame

When Gero Hütter had the idea of his life, he was working as a ward doctor in the oncology department of the Benjamin Franklin University Hospital in Berlin. The idea was as simple as it was brilliant. Any one of his colleagues could have come up with it, Hütter thought. He was afraid that the sceptics who would try and denigrate his idea before it could actually turn into a project. And he was afraid that the ambitious types with influence would snatch his idea away and pretend it was theirs.

Back then, in the stiff hierarchy of the hospital, Hütter felt like a nobody. “It’s like being in the trenches,” he used to say. “If you stick your head out, the bullets whizz past your ears.” He was worn out by the ward’s daily routine and had little time to spend on research. The cast-iron law that ruled at the Benjamin Franklin Hospital, however, was: “Only he who writes, stays.”

At the age of 38, Hütter was not too old for an academic career but he often felt he was. Others had already made it as professors or senior physicians with their own areas of research. They were the ones with straight career paths, the best ‘A’ level results, medical studies at the age of 19, and PhDs at the age of 25. Hütter’s career path had twisted and turned. Brought up in a protective middle-class home in Celle, Lower Saxony, he’d had every opportunity to discover his talents early on but they had remained hidden back then.

He’d always seen himself in the shadow of his brother, five years his elder, who got better grades and developed a passion for mathematics at an early age, knowing from the start that one day he would become an engineer.

Hütter, on the other hand, daydreamed of excavating the ruins of great cities, like the architect Heinrich Schliemann. But after scraping through his ‘A’ levels, he drifted into a phase lacking direction during which time he matriculated for a course in Ancient Studies at the University of Cologne. He soon reached a stage where he could no longer remember why he was studying at all – and decided to get his civilian service over with instead. In hospital, he found the patients’ gratitude very satisfying. He accumulated waiting semesters for a course in Medicine and was finally accepted at the Freie Universität Berlin at the age of 23.

For the first time in his life, he felt a sense of purpose. Soon, the textbooks didn’t satisfy him so he subscribed to as many specialist journals as his modest budget would allow.

In one of these in 1996, he read a congress report that was astonishing: it reported that some people are not able to fall sick with the immune deficiency disease Aids: they have an in-born resistance. A hereditary gene defect protects them, one that presumably gave their ancestors an advantage in surviving the great epidemics of the plague and smallpox. People carried this genetic mutation as far back as the Bronze Age. Since then, it has spread over centuries across Central and Eastern Europe but it is practically non-existent among Africans and Asians. Every tenth European carries the mutated gene but even this is not sufficient for 100% natural resistance to Aids. For this to occur, the sister gene on the sister chromosome has to be mutated too. This happens in one per cent of all Europeans. These people are immune against AIDS.

Hütter took note of this curious fact for some reason. Aids, back then, was considered an incurable, fatal disease and he was scared of it. He was sure he was never going to make this stigmatised disease his research area. But how wrong he was.

Tim Brown was the reverse of Hütter. His path in life had begun as a straight one: Economic studies in Seattle, then a career as a banker. When he was 24 years old, his job began to bore him and he developed an insatiable hunger for new horizons. In summer 1991, he packed his bag with a few belongings and flew from Seattle to Barcelona, notorious for its excessive nightlife and gay scene. Tim, who was youthful-looking with a slim build, was idolised by gay men and lived his new lifestyle to the hilt. He frequently changed sexual partners, lived in their apartments and took on casual jobs as an English teacher and translator to make ends meet.

He had always insisted on using condoms, he later said to the doctors. A broad-shouldered security guard from the city council had made him reckless, however. The man came inside him. Tim felt it, and grew angry, but it was too late. From then on, he had an uneasy feeling and in summer 1995, this was confirmed: he tested HIV positive. By that time he was already living in Berlin. At first, the shock hit him hard, as he thought he would only have another two years or so to live. But at the time, a new combination of medication had come onto the market. Aids lost its shock factor and for many of those affected, it became a chronic but treatable disease. Tim was one of the lucky ones: he did not experience any of the extreme side effects of the medication. He got used to living with HIV, ate a healthier diet and did more sport. He also put a stop to his sexual promiscuity when he met Matthias, a divorced father with two daughters from former East Germany who had only acknowledged his homosexuality late in life. Tim conformed to the values that were important to his new partner: fidelity and monogamy. Matthias helped Tim settle down and he found in Germany what had been missing in America: a family. Matthias' daughters loved him, and his parents and siblings accepted him as a son- and brother-in-law.

In summer 2006, this new life was suddenly over. It began with a leaden exhaustion that refused to lift after he got up. Then pain, rolling in waves through his whole body, sometimes affecting his head, joints, or stomach. One afternoon, he collapsed on a jog through the park and Matthias had to come and collect him. The emergency doctor diagnosed severe anaemia and sent him to hospital.

Gero Hütter looked at the hastily scribbled admittance form. Diagnosis: suspected leukaemia, HIV infection known since 1996 but not yet broken out. A rare combination, he thought. And catastrophic blood test results! Immediate bone marrow aspiration to verify the diagnosis and a central venal catheter for chemotherapy were necessary. He would have to do this himself as his colleague, Daniel Nowak, was new to the ward, a young researcher who had spent a year in the laboratory after his studies and so had little clinical experience.

The patient lay alone in his room. He seemed fragile, too thin for one metre seventy-five, and his warm brown eyes stared out of his hollow-cheeked face. It was the stigma of many people with long-term HIV infections, a side effect of the combined medical treatment. The medication dissolves the subcutaneous fatty tissue, especially around the cheeks. Both men talked for a while and Hütter was very concerned not to make any mistakes. With good reason: inserting a vein catheter carried the risk of hitting an artery. It was a procedure that could end in a bloodbath. He was sweating and his heart was pounding, his old fear of becoming infected with HIV surfacing.

Tim Brown liked the young doctor from the outset. He seemed less smug than the others, was competent and good-looking in a subtle way with his thickset build, brown, combed-back hair and the set look in his eyes behind his frameless glasses, a look that Tim would have gladly relieved him of. Definitely gay, Tim thought back then.

The incredible idea came to Hütter when he first saw Tim’s laboratory test results. It was as if, after seeing the admittance form for the first time, his brain had started up a search programme. Now it produced its result: the article that Hütter had read as a student about people who were resistant to Aids.

Tim was suffering – there was no longer any doubt – from acute myeloid leukaemia, in other words, blood cancer. A clone of malignant cells was proliferating in his bone marrow that would soon attack other organs. The chances of survival without chemotherapy stood at zero per cent. He would need four cycles. Even then, only every fifth patient was cured; the others suffered relapses and needed a stem cell transplant.

This was where the extraordinary chance of a lifetime came into it: Hütter had to find a stem cell donor who was immune against Aids. The odds of success stood at 1 to one hundred. Before the transplant, Tim’s immune system would be completely destroyed by cytotoxins and radiation, and lack the white blood corpuscles that acted as a Trojan horse for HIV.

However, the virus would no longer be able to penetrate the new immune cells – those of the donor. That’s because a docking site called CCR5 would be missing, where HIV normally entered. It would be as if someone had taken the key out of the door.

Tim Brown would be the first person in the world to be cured of the HIV infection.

“Is that really true?” asked Chief Physician Igor Blau, rubbing his grey beard as they stood in the corridor after visiting the patient. “Has no one ever thought of it before?”

“I trawled through all the documentation and I couldn’t find anything,” said Hütter.

“But you know that these kind of experiments aren’t usually published if they’re unsuccessful?”

“Of course. But what have we got to lose?”

Blau lifted his index finger as if he had been struck by inspiration and a smile spread across his face.

“That’s brilliant! Let’s go and see the boss straight away!”

This was exactly what Hütter had been afraid of. That too many people would get wind of his idea. And that they would “shoot” the lowly assistant doctor , in academic jargon.

The chief physician carried the official title of director. He was upper class – a descendant of the Singer dynasty – loved opera and was not far off retirement. He ran the haematology department in an old-fashioned style that reminded Hütter of an absolutist ruler. Blau thought that this was an exaggeration – he enjoyed a good rapport with the boss and respected him for his successes. Perhaps that’s why Hütter reckoned his chances were high and that with Blau’s support, his idea would be safe. Blau himself had had to leave the Charité a few years previously as a relic of the GDR era, only to re-establish himself once more. Hütter had managed the ward for a long time under his direction and they had a tacit understanding. He regarded Blau as his mentor.

The director would either give the thumbs up or thumbs down. If he gave the thumbs down, Blau would still find a way, Hütter was sure. After all, he had the best contacts to all the stem cell donor organisations in Germany.

So there they stood, in front of the gigantic desk. Like lambs to the slaughter, Hütter thought and he thought back to his job interview. At the time, he had enthusiastically reached out his hand to the director, who hadn’t taken it.

But this time, the director said, “That’s fantastic! Keep at it night and day, Mr Hütter. We won’t let anyone take this away from us!”

Soon they were standing outside the door again and Hütter, relieved, asked Blau to keep the project quiet for as long as possible. Most of all, he wanted to sidestep a certain doctor, Professor U., the director of the department for stem cell transplants. Hütter had only had one clash with Professor U. but since that argument, he knew he would never be able to work with him again. And he was to be proved right on this point.

Tim’s insides went numb when he heard the diagnosis. He’d taken on life with all its dangers and now he was standing at the edge of a chasm through no fault of his own. Matthias cried with him.

The chemotherapy was a life-threatening experience. It destroyed not only Tim’s cancer cells but also his immune system. During the third cycle, bacteria flooded his body resulting in septicaemia. His lungs filled with watery exudate, he struggled to breathe and his temperature rose to over 41 degrees. When the doctors wanted to put him into an artificial coma to spare him the ordeal, he refused at first, believing he would never wake up again. Some hours later, he gave in. Matthias came and they exchanged last words, thinking it might be their final goodbye.

One decisive factor in the search for a suitable stem cell donor is characteristics of protein on the cell surface that are encoded under the abbreviation HLA. Those of the donor and recipient have to correspond very highly. If they diverge too much, there is a risk that the recipient will reject the foreign stem cells. That is fatal. The patient’s own immune system can no longer take over, having been destroyed. Equally, the donor stem cells can attack the host. This has equally fatal consequences.

Four million Germans are collated in five donor databases and there are 17 million donors worldwide. The chances of finding a suitable donor vary greatly from person to person. Every fifth patient looks for a genetic twin in vain.

Igor Blau’s computer was linked to all the databases worldwide. He would look for a potential donor for Tim Brown even if he wasn’t sure that he’d ever need one. That was part of the routine.

The code that would save Tim’s life consisted of ten letters and sixteen numbers. The search took a few minutes. When the result came up on the screen, the chief physician rubbed his eyes in astonishment and called Hütter over.

“Look at that!” he said and handed his ward doctor a pile of papers. “You don’t even have to check the number. There are 232 potential donors!”

Hütter’s heart leapt. They’d gone from a theoretical possibility to a real opportunity. He glanced over the pages and did the calculations in his head: according to statistical probability, one per cent of the 232 people would be resistant against HIV. That meant two possible donors whose stem cells would be able to save Tim not only from cancer but also from the looming risk of Aids.

When Hütter presented his idea to Tim that same day, the hardest days of his life were only just over. Still, he was working out daily with grim determination to try and regain his strength, doing sit-ups on a gym mat that Matthias had brought along. Tim already knew that his chances were not very high. The cancer was highly likely to recur: due to the septicaemia, the chemotherapy treatment had been stopped after two and a half cycles. “I haven’t got a problem with HIV,” he said. “But if you find a suitable donor and I have a relapse, why not?” Hütter understood Tim’s cautious reaction, mostly due to the daunting prospect of a stem cell transplant. But secretly, he’d hoped for more enthusiasm.

They nicknamed Daniel Nowack the “big brain” even though the young assistant doctor was shy and modest. Hütter had introduced him to the clinic’s daily routine. They had a casual friendship and sometimes went for a drink after work.

When Nowack talked about his research projects on molecular genetics, Hütter was impressed by his scientific expertise, coupled with meticulous precision. A technocrat who would make a career in the laboratory, he thought, and was reminded of his brother. He and Nowack, he thought, would make a perfect team. “But not a word to anyone else,” he impressed upon him. This team of three, Hütter, Nowack and Blau, was now ready to set off on an adventure into the unknown.

They needed a genetic test to re-examine the potential 232 donors for resistance to HIV. But this kind of test didn’t exist on the market. “Not a big deal,” said Nowack. One afternoon, he created a construction model for a molecule on his computer that would find the gene segment they were looking for in the genetic substance. He sent the formula to a laboratory where it was put together according to his plan.

Now he could find the segment where the decisive gene occurred in each of the donors’ genetic substance. The final step was to use a tried and tested method to locate the one mutated gene that carried the code of HIV resistance among the many “normal” gene segments.

In doing so, he would use electricity. The reason for this was that the gene of HIV resistance was noticeably lighter: there was a large piece missing that had got lost in evolution. And so he would organise a little race in which this gene segment would move forward faster than the others. First he had to spread the genetic substance of all the potential donors on gel and then set up an electric field. The genetic substance would move in the direction of the positive pole, and the one, shorter gene segment would make it the furthest. The person it belonged to would be the donor they were looking for.

Contacting donors was a little trickier because the law prescribed many formalities. Each person had to be contacted by the foundation he was registered with. Then the donor would have to agree to a genetic test in the knowledge that the discovery of a mutated gene might have unforeseen consequences: it may have health drawbacks that the donor was hitherto unaware of. All this required work involving great diligence and time, and the foundations would want to be paid for it. But there was little money available because Hütter had done without making a research application. Time was just too short. He negotiated with the foundations, tried to get them interested, drew up project plans and explanatory sheets.

In autumn 2006 – Tim Brown had long since been released from hospital – the blood samples from the donors arrived by post. Nowack now had many other projects on the go and gave the routine work to his student intern.

One afternoon, the young man came up to him and said: “We have one!” It was Donor 61. Nowack felt a shiver go down his spine. He knew they were onto something big. Had he done everything correctly? Chosen the correct gene segment? He buried himself in the laboratory, checked all the details, and analysed the gene segment from Donor 61 – each building block and each nucleotide. Everything added up.

For Hütter, Donor 61 was no cause for celebration. He felt schizophrenic. As a scientist, he longed for the opportunity of a unique attempt to cure his patient. As a doctor, he had to hope that Tim would manage to make it through without a relapse and without all their efforts so far being in vain.

Should he now let the director of the department of stem cell transplants, Professor U., in on the secret? It was his last chance to do so and therefore avoid him being left out. But Hütter decided against it once more. He felt uneasy. He gathered all his documentation in a pile and decided not to think of Tim Brown’s case any more.

The department for stem cell transplants had a bell. Behind two sliding glass doors, an air lock opened where visitors could disinfect their hands and doctors’ coats, and put on gloves and facemasks. In front of the six rooms, there was a further hygiene air lock.

Tim Brown had returned five months after his discharge and had been admitted straight into this department. On his night table stood a wooden guardian angel. It was a present from a friend of his: “He’s watching over you to make sure nothing happens”. In bed lay his teddy. The preparations would take two weeks starting with the infusion of cytotoxins.

Then, shortly before his transplant, he received full body radiation: transfer into the Charité cellar, facemask, cold neon light and classical music, an hour completely motionless. Invisible rays completely destroyed the bone marrow that had protected his body for 41 years from the daily attack of microbes and had done the job tolerably well even now that he was seriously ill. But his old immune system had to be destroyed, as it would reject the donor's cells otherwise.

When this procedure was over, Tim was as helpless as a prematurely-born foetus. The most harmless of infections could now destroy him. There was no turning back and he'd never felt so alone.

But at the same time he was happy. He felt that the experiment, which had not mattered to him half a year ago, held something big in store. He saw it as his "holy mission" to see it through.

The day of the transplant, 16 February 2007. Matthias and one of his daughters had come. Tim held a speech for the world, Matthias filmed him with a video camera.

"I'm the first person in the world who is receiving a stem cell transplant to overcome HIV (…) and I hope that this experiment will help scientists cure people of Aids in the future."

The sac: 300 millilitres of blood-red liquid. Tim knew that the donor was male, German, young and lived in New York. He had travelled to Germany especially to donate his stem cells and was spending three days in hospital. He was given medication to accelerate the maturation of stem cells in his bone marrow and then they were washed out into his blood. Afterwards, his blood was run through a machine using centrifuge, and the stem cells were filtered out. 400 million stem cells, which would soon develop into white blood corpuscles – the start-up capital for Tim's new life.

Contrary to what Tim had believed, the transplant was not an operation. A doctor hung a sac by his bed, attached the tube to one of Tim's veins and set the counter to "flow", noting the time. Then Tim could watch the life-saving liquid enter his body, drop by drop.

The days afterwards, he felt the terrible constriction of his narrow hospital room. All he could see was the view onto the park, the distant church tower, and the branches of the tree outside. Then, the endless juddering of the emergency helicopter, the nurses' energetic steps in the corridor: he could only bear it by cutting himself off. Sleeping mask, earplugs, so as not to see or hear anything. He was terrified in case something awful happened again. A third of all stem cell transplant patients die in the first year from the toxicity of the preparations, from infections, or due to incompatibility between donor and recipient.

After a few days, Tim stood up for the first time on wobbly legs in his room. Then, with a girlfriend, he secretly disappeared from the hospital – the doctors had prescribed complete bed rest. But he needed the open sky above him and wanted to see the dampness of his breath in the winter air, hear the sounds of the street, and feel that he was still alive.

How much did Professor U. know about what was going on in his department? Hütter was convinced that he knew nothing up to this point. But in fact Igor Blau, feeling duty bound, had reported to U. what was planned. And U. had urged Blau to keep him up-to-date with developments. But Hütter, the director of this film, the puppet master, had kept quiet. Just as everyone had, or so he thought. His strategy would go to plan and the experiment would be carried out behind U.'s back.

As Blau explained only much later, at that point it had no longer been possible to keep things secret. Professor U. never mentioned to Hütter that he knew he was trying to sidestep him. U. merely took no notice of him: a lowly assistant doctor was unimportant in the hospital hierarchy.

The HIV infection disappeared from Tim's blood after the transplant. That was no surprise to anyone. After all, its main domicile had been Tim's immune cells, which were now destroyed by radiation therapy and cytotoxins. But perhaps it was just hiding in a safer place, such as Tim's nerve cells.

The American now entered a fragile stage. Doctors had to constantly check his blood so as not to miss the moment when the lethal virus returned. Tim had been taken off the medication that had previously kept the virus in check before the transplant – its side effects were simply too dangerous for fresh stem cell recipients.

Now the doctors had to address the question of whether Tim Brown would ever need medication again. In case the experiment didn't work, Hütter was expecting an imminent, dangerous explosion of the concentration of the virus in Tim's blood.

After two weeks, Tim was discharged but came back once a week for blood tests. The virus had disappeared without a trace. Had Hütter's simple idea really worked? They would have to wait 120 days before they could consider it proven.

But after a few weeks, the whole experiment was jeopardised. Later, those involved told different versions of why this was. One morning, Tim didn't show up for his blood test and at first, Hütter didn't know where to find him. Later, Tim explained that Professor U. had told him he didn't need to come to the hospital any more. It was sufficient for him to be treated by his occupational oncologist. What had led the professor to take this step? Hütter wondered. Did he want to break the contact between the hospital and the patient? Did he bank on the chance that the oncologist would simply put Tim back on HIV medication because he was reluctant to incur risks and costs? Then there would be no way of telling why the virus remained invisible – due to the stem cell transplant or just due to the medication. Did U. want to prevent the sensation that was clearly on the horizon from being scientifically proven, without doubt? All of this went through Hütter's mind but he never spoke to U. directly.

Another doctor involved believed it was Tim who couldn't get along with Professor U. and had therefore changed surgeries. No matter how it had happened, after a few explanatory telephone calls, the occupational oncologist began to work in close collaboration with the clinic. Every week, Hütter was sent the new lab results.

After 120 days, he was able to enjoy a quiet triumph. HIV was not present in Tim's body. It looked as if his patient would no longer need medication.

If Hütter had been looking for world fame, he could have gone public at this point. Headlines in the tabloid press would have been guaranteed. But Hütter wanted more. With his discovery, he wanted to scale the Mount Olympus of all doctors: the *New England Journal of Medicine.* Founded in 1812 in Massachusetts, it is the most frequently cited medical journal in the world. A publication in this journal as a leading author is the indisputable zenith of any scientific work.

Hütter reckoned his chances were good. But everything was to turn out differently – for him, and for Tim Brown.

"Now you have to live as virtuously as a monk!" said the director. A second strain of HIV existed, continued the doctor, that was much more rare – but Tim was not immune against it even with his new blood cells. Tim simply answered: "Yes, I will try." But soon his resolve broke and he fell headlong into an affair.

Matthias couldn't forgive him. He would stick by him but only as a good friend, no longer as a partner.

Three quarters of a year flew by. Matthias fell in love with Paul, an artist. Tim started to enjoy life again to the full. At Christmas 2008, he flew to San Francisco where he was planning on celebrating New Year's Eve but had to be rushed to hospital with pneumonia. The doctors established that his white blood corpuscle values had hit rock bottom. "Oh shit, it's starting up again," thought Tim and remembered Hütter's words: a relapse was possible even if just *one* of his old immune cells had lodged itself in a niche somewhere.

Back in Berlin, he had to undergo the same nightmarish procedure all over again: chemotherapy, full body radiation, stem cell transplant. The young German donor had to come over from New York for a second time. Brown prayed that his aeroplane wouldn't crash.

At first, it seemed as if the treatment had been successful. But all of a sudden, unforeseen complications began to accumulate: Tim's new stem cells didn't produce enough platelets, which meant that his blood failed to clot. First he bled in his right eye, then his left, making him temporarily blind. His thoughts slowed down, and so did his movements. Then came an attack of meningitis from an unknown cause. The neurosurgeons punctured his brain with serious consequences: air penetrated and filled the cavities, compressing his brain matter. Tim no longer knew where he was or what his name was. His limbs were paralysed. Soon, he fell into a coma-like state. His physical state declined more and more rapidly.

The doctors gave up. Hütter said to Matthias: “I don’t think he’s going to make it.” He felt powerless to stand by and watch the life of his most important patient peter away. And no one in the hospital could even say why.

But Matthias didn’t want to accept it. The whole fight for nothing? Was this medical miracle to have such a tragic end? He took Tim home with him. His new partner, Paul, cooked and secretly mixed meat into the food so that Tim – a strict vegetarian – would recuperate his strength. Matthias’ sister, a nurse by profession, moved into their flat and took over his care.

With the help of his ex-boyfriend, Tim survived. In a rehabilitation clinic for neurology patients near Berlin, he struggled back to life, step by step. He learned to speak again and to walk, and slowly regained his memory. What exactly damaged his brain remains a mystery to the doctors, even today.

Gero Hütter believed that it was a mixture of all the factors together: the chemotherapy, the cytotoxins that had destroyed his immune system twice, full body radiation treatment twice, the endless medication … Hütter began to see his success in another light. But it was a small comfort that the HIV infection had not returned.

Dorit Hütter was woken up at half past six on the morning of the 12.11.2008 by the sound of an incoming text message on her phone. Gero was still asleep next to her. A mutual friend had written: “Crazy, your husband is on the front page of the BILD newspaper!!!” Gero Hütter’s face drained of colour. Ten minutes later, he rushed out of the house without breakfast. How had this happened? First, five days ago, the *Wall Street Journal*, and now the BILD. A journalist had phoned him the day before but he had refused to comment and had hung up.

The experiment was in a highly sensitive phase. *The New England Journal of Medicine* had checked his work for more than a year. Time after time, the assessors had asked for subsequent improvements but in the end they had sounded very positive. Hütter was excitedly looking forward to being accepted for publication.

But having this news first celebrated in the media could lead to a catastrophe. Sometimes, work was rejected for this very reason. At the kiosk on the way to work at the hospital, he saw the headlines: “Sensation! Berlin doctor cures Aids patient.” And in small print below: “Humanity has been waiting for this moment.”

Hütter’s mobile phone rang. It was the head of the hospital press department. There was to be a press conference at eleven o’clock in the Charité. Hütter had dreamt of scientific fame but he had never liked being in the spotlight. A flurry of photographers’ flashes, TV cameras, questions in English. Hütter sat on the podium between his boss and the director of research at the Charité. Everything went smoothly.

The biggest catastrophe didn’t occur until an hour later. It was an email from Professor U. to Jeffrey Drazen, the chief editor of the *New England Journal of Medicine*. Hütter was copied into the email. U. wanted to withdraw his name from the list of authors – without naming the reason.

Hütter froze. It was the worst thing that could happen now. An author withdrawing his name on the brink of a manuscript being accepted for publication in the most renowned medical journal in the world – this could be interpreted by the evaluators as a sign that the results were falsified. The man had simply got cold feet. No one in the US would check to see if, in fact, someone felt snubbed.

If only he had fought not to have U.’s name on the list of authors. He’d given in when someone with more influence than he had pointed out that it would be good for “peaceful relations”. It was the usual game of deceit played by many scientists who were tinkering with their careers: you include me on your paper, and I’ll include you on mine. Many who wanted to get somewhere joined in, as everyone needed a long list of publications. The most highly acclaimed journal in the medical world checked every word, every figure in a publication. But, Hütter thought, they didn’t check thoroughly enough who had actually made a contribution.

His work and the work of his colleagues was now in danger. It was possible that they wouldn’t be able to publish the study in any other distinguished journal either. Who would want to take on a project where the accusation of fraudulent research hung in the air? The world would lose an insight that might propel science forward by miles, feared Hütter.

U. was later asked to go and see the boss but their conversation took place behind closed doors. Two days later, he sent the journal a second email in which he explained that his withdrawal from authorship had nothing to do with the scientific content of the manuscript, but that he had taken the step for “personal reasons”. Many years later, in reply to an enquiry on this topic, U. simply said: “I felt that the way in which this case was made public inappropriate.”

Summer 2012. Hütter’s work was published on 12 February 2009 in the *New England Journal of Medicine* despite U.’s e-mail. The events surrounding the “Berlin Patient” had long since been discussed in the HIV community worldwide. Top-notch experts had discussed Hütter’s results long before its publication at congresses, and no one had doubted the credibility of the results. The director himself had stepped in and written letters, looked for influential advocates – and he had given Hütter the honourable position of first author rather than “picking him off” at the last minute. This was not at all self-evident in the world of science.

Throughout the world, no second patient has been treated with the same therapy approach. The genetic mutation that protects people from Aids is as rare as patients suffering from leukaemia and HIV, *and* for whom there happen to be a few dozen or even hundreds of potential stem cell donors. It was the jackpot in the lottery.

And yet it was Hütter who was the first to prove that it is possible to cure patients of Aids. In the USA, millions of dollars are poured into research projects that are built on this knowledge. Doctors are trying to find a cure based on gene therapy. They flood modified genetic substance into the immune cells of their patients in the hope of achieving what Hütter achieved with Tim Brown – that the docking stations, which are used by HIV like a doorknob to enter cells, permanently disappear.

Gero Hütter, celebrated in the media as “the new research star at the Charité” has no share in these projects. In Berlin, he was not promoted to senior physician, which would have been his due after his long stint as a ward doctor. His application for a 12-month sabbatical to continue the HIV project was rejected by the Charité. He finally received a position as a chief physician in Mannheim at the German Red Cross Blood Donor Service where, alongside his clinical work, he researches the genetic mutation that makes people immune against Aids. He is currently looking for a donor for a second “Berlin Patient”.

But he knows that it is not enough for a successful career in the medical world to achieve a globally celebrated milestone. You also need to have a certain kind of character, belong to a clique of influential people and preferably concentrate on an area of research in which you’ve already cut your teeth. For Hütter, that would be tumour research, not Aids.

Two years later, Hütter is on first name terms with his patient Tim Brown. They describe themselves as friends and meet at congresses where Hütter presents his case study and Tim talks about his experiences.

Nowadays, Tim lives in a 10-square-metre room infested with cockroaches in San Francisco in a home for drug addicts and the mentally ill. He has found a new partner, a friend from his youth, but the relationship goes through extreme highs and lows and he misses the stability of Matthias.

After his serious bout of meningitis, it is unlikely that he will ever be able to work again. But he is grateful for the fact that he is still alive and will probably never have to take HIV medication again. It was a life that was lived according to the punch clock, having to stick to precise times each day, having to check before he left the house whether he’d taken his tablets with him. In his present situation, he would probably not manage.

The HIV infection has not shown up in his blood to this day. However, at the beginning of 2012, his doctor (a respected Aids researcher in the USA) found virus material in Tim’s colon and stirred up a scientific debate. Had the infection just lain dormant? But the virus material, as was established after several examinations, belonged to another kind of HIV infection. Perhaps Tim had re-infected himself, so the speculations went. When the colonoscopy was repeated in another institute, there were no traces of the virus. Tim Brown, therefore, is deemed to be the first and only person worldwide who has been successfully cured of HIV.

When he comes to Germany to hold a lecture, Matthias and Paul put him up. Matthias says it’s a scandal that the “Berlin Patient”, who gave science such valuable knowledge, has to live off charity. It is the duty of those who receive and spend millions in research funding to finance a humane existence for Tim Brown.