

- April 11th, 2019

- From issue 15/2019

- health

wishful thinking

The incurable nervous disease ALS paralyzes patients so comprehensively that they are no longer able to communicate. Professor Niels Birbaumer from Tübingen claims to be able to decipher the thoughts of these people. Birbaumer's colleagues doubt this. But only a young computer scientist dares to take action against the star researcher.

- By Patrick Bauer

- Patrick Illinger

- and Till Krause

A neoprene cap like this is equipped with sensors. It measures brain activity. Professor Niels Birbaumer claims to be able to communicate with completely paralyzed patients in this way.

Photo: Nadio Verlyck/Wyss Center/dpa/picture alliance

- 
- 
- 

Nine years ago, the professor saw the key to the imprisoned thoughts in a ground floor apartment in Hamburg-Dulsberg.

Waltraut Faehnrich, 73, lies there, today as then, only moved by the rhythmic panting of the ventilator, his eyes closed, his mouth open, his tongue looking out.

Joachim Faehnrich glued a photo wallpaper to the wall behind the sickbed, from which his wife could not get out. The wallpaper shows a wide open window overlooking the Blue Lagoon of the Dominican Republic. The Faehnrichs often bathed in this shimmering turquoise water. For many years they lived with their children in the island state. Joachim Faehnrich had a construction company in Germany until he - chronically blocked sinuses - could finally breathe and think freely again in a holiday alone in the Caribbean. He called Waltraut: You, little mouse, I'll stay here! Waltraut Faehnrich, a snapper like him, just as intrepid, unwound everything, packed the things and followed with the two daughters and the son. Together they would do everything.

Illustration: Rugar Benedikt

-•

### BCI: Brain Computer Interface

The technique called "brain-computer interface" is an apparatus that connects a human brain directly to a computer. Among other things, it is used to facilitate mobility and communication for people who no longer have control over their language and muscles. BCIs can be used to control prostheses or wheelchairs, for example. But the technology can also help to spell. Selecting letters using an EEG cap that measures brain waves works amazingly well. As soon as the desired letter appears on a screen, people should think of a dance, for example, and the BCI recognizes this signal.

Photo: Nadio Verlyck/Wyss Center/dpa/picture alliance

-•

### NIRS: Near Infrared Spectroscopy

In addition to recording the electrical activity of the brain using EEG, the measurement of the blood flow in brain convolutions offers another opportunity to decipher the thought process. Small infrared light sources shine through the skull bone into the brain, while sensors measure the scattered light. The signals show how strongly brain areas are supplied with oxygen. In "functional near-infrared spectroscopy" (fNIRS), blood saturation can be monitored during various thought processes with a cap full of sensors.

Illustration: Rugar Benedikt

Previous image 1/5 Next image

Birbaumer did not want to accept that he could not penetrate to the trapped ones. That he did not know how they think. There had to be something else. He set out to search for eleven years.

So he came to the Faehnrichs.

The professor found in Waltraut Faehnrich, not long gone but ungraspable, the ideal patient to prove that even the thoughts of completely enclosed people can be deciphered. Maybe it's just too exhausting for people like Faehnrich to even think whole sentences purposefully? Birbaumer wanted to go deeper into the brain, where the thoughts originate. He put a neoprene cap on Faehnrich, which was studded with sensors and connected to a laptop - a "Brain Computer Interface", BCI. The blood circulation of the brain is measured by means of infrared (NIRS). The idea is that different thoughts produce certain blood circulation patterns, that a yes looks different than a no. <sup>[P]</sup><sub>SEP</sub>

"Hamburg is on the Elbe."

"Berlin is the capital of Spain."

"You're sitting in a Porsche right now."

Birbaumer and his colleagues Waltraut Faehnrich asked such questions. After 15 seconds the result from the speakers of the special computer quaked: "Your answer was recognized as no", "Your answer was recognized as yes".

Joachim Faehnrich asked his wife more personal questions.

"Do you have pain?"

"Do you like it when the kids come to visit?"

"Is Storm of Love your favorite series?"

For months, Birbaumer tried out the technology until he saw a quota of more than seventy percent as correctly recognized answers and believed he could present samples that were strong enough to convince the experts: "There was something. Someone. Waltraut Faehnrich, he believed, spoke to them.

In 2014, Birbaumer and his colleagues published a scientific essay in the Journal Neurology about Waltraut Faehnrich and his success in bringing her mind back to light after years of darkness. He also published videos of his experiments with her, showing him standing with Joachim Faehnrich in front of Waltraut Faehnrich and joking. Birbaumer says in the film: "We are showing this in Hollywood."

Joachim Faehnrich wanted such a device at home so that he could communicate with his wife in everyday life. But the cap, hardware and software cost around 40,000 euros - which her health insurance company was not prepared to pay. The Faehnrichs went to the Hamburg Social Court, where the case was heard in October 2015. As proof of the effectiveness of the machine, a television report about the Faehnrichs was recorded in which Birbaumer had his say. There are also two scientific essays in the case files, both written by Birbaumer. The only witness who was summoned was Birbaumer: Niels Birbaumer, who emphasized in court that his technique recognizes "whether a patient thinks yes or no". The court was convinced. The health insurance company had to pay for the device. A success that means that other patients could now also access such devices more easily.

For the Faehnrichs, the professor is a miracle.

For the professor, the Faehnrichs are a gift.

Two years later, in the spring of 2017, another article by Birbaumer's team appeared in the US journal PLOS Biology, which gave the professor a new nickname: the mind reader. In the study, Birbaumer described the system, which had been tested on Waltraut Faehnrich, in the following

Issue number 15

What do you think, man?

A professor from Tübingen makes headlines all over the world: He is said to have succeeded in deciphering the thoughts of completely paralyzed patients. For many relatives, he is the last hope to communicate with these people. Research by SZ-Magazin: The supposed miracle is in truth a scandal.

To the magazine

Today, she can't see this wallpaper without special glasses that hold her eyelids up, nor can she see the portraits of her six grandchildren next to it. Waltraut Faehnrich is also able to hear, smell and feel touch, she perceives everything - but can do nothing at all. Every few hours, one of the nurses who has been working shifts for the Faehnrichs since they were diagnosed twelve years ago - when their homesickness led them back to Hamburg - has to turn the 73-year-old over so that the skin doesn't get sore. And lift them into the huge wheelchair that Joachim Faehnrich pushes through the neighbourhood in the afternoon and sometimes into his transporter to drive to the next Helene Fischer concert or with his family to Denmark or even Spain. Waltraut Faehnrich is always there. For her husband she is a living spirit in a lifeless body.

ALS, amyotrophic lateral sclerosis, is an incurable nervous disease. Gradually, the brain loses control of the muscles. It can begin with a numb foot or with difficulty swallowing, until in the worst case a state of almost complete paralysis occurs, with full consciousness. This is called Locked-in-Syndrome, LIS for short. If the patient can no longer even move his eyes, and so it was with Waltraut Faehnrich after three years, doctors speak of Completely Locked-in Syndrome, CLIS, the complete confinement.

The vast majority of ALS patients decide at an early stage against artificial respiration for fear of this condition.

The vast majority of ALS patients decide at an early stage against artificial respiration for fear of this condition. People like Waltraut Faehnrich, who live in the terminal stage of the disease, connected to a ventilator, artificially fed, there are few in Germany, like many exactly, no one knows, one suspects that some are mistaken for coma patients. They would then not only be trapped. Nobody would know that they are still there.

On the family picture of 2007 - the first Christmas after the diagnosis - Waltraut Faehnrich is already sitting in a wheelchair, smiling an exhausting smile. The Faehnrichs did not make the decision easy for themselves. Did she want to be kept alive when the strength leaves her body? At night Joachim Faehnrich lay awake and listened to his wife to see if the air had disappeared again. They asked the children to go home, and Waltraut Faehnrich announced that she would have ventilation. They had read a lot and learned about what might come. Nevertheless, it was a journey into the unknown. But together they would do anything.

At first the voice disappeared. Then Waltraut Faehnrich couldn't move a finger. Then not even her eyelids, with which she had been able to operate the "Eyetracker", a speech computer controlled with her eyes. No more yes, no more no, nothing. Waltraut Faehnrich was so close, so far away.

The husband did not want to accept that he could not communicate with her. That he no longer knew what she was thinking. She was still there after all. Joachim Faehnrich set out to search for three years. A friend finally recommended the professor from Tübingen to him.

Prof. Dr. phil. Dr. h.c. mult. Niels-Peter Birbaumer, born in the same year as Waltraut Faehnrich, only three days earlier, psychologist and neuroscientist, is known for approaching his research topics with unusual, often brilliant ideas. Birbaumer, small, wiry, white-haired, is an impressive personality, empathetic, multilingual, charming. After a difficult youth, even a phase as a petty criminal, he created an outstanding career in science. At the age of 29, Birbaumer became a professor in Tübingen, where he later took over the chair of Medical Psychology and Behavioural Neurobiology. His curriculum vitae includes more than 600 scientific publications, almost thirty books, four

honorary doctorates and numerous awards, including the Leibniz Prize, the highest researcher award in Germany.

Niels Birbaumer was born on 11 May 1945 in Ottau in what was then Czechoslovakia. He grew up with four siblings in Vienna. There he studied psychology and neurophysiology. After his doctorate, at the age of 23, he was expelled from the university for political agitation. From 1975 he was professor in Tübingen, where he headed the Institute for Medical Psychology and Behavioural Neurobiology until his retirement in 2013.

Photo: Thomas Dashuber

Over the years Birbaumer repeatedly made the headlines with some daring theories. He expressed the conviction that the brain of sociopathic criminals could be reprogrammed and their ability for empathy and self-control restored. Afterwards, from 1995 onwards, he devoted himself above all to one goal: making contact with people in a locked-in state. Birbaumer let himself be paralysed with the South American arrow poison Curare to feel for a few hours what it is like not to come out of oneself. Although LIS can also be triggered by other diseases or strokes, people with the nervous disease ALS are particularly interesting for researchers because the disease affects less the brain than the muscles, which sooner or later all fail their service. Only the mind remains awake.

In 1999 Birbaumer achieved his first sensation: with a hood that records an electroencephalogram, an EEG - the electrical activity of the brain - and a device that converts brain waves into screen signals, a locked-in patient could think letters and even dictate entire sentences with the power of his thoughts.

Niels Birbaumer published his breakthrough in Nature, the most renowned scientific journal in the world, but it did not go any further: Birbaumer's EEG method worked in locked-in patients, but not in completely locked-in patients. Did thinking also die with the last muscle, with the last possibility to make oneself felt, for example? Is man no longer a human being if he is not understood by anyone? One theory says that the human brain changes into a kind of twilight state when there is no more possibility to formulate thoughts and express wishes.

-•

ALS: Amyotrophic lateral sclerosis

In the human body, nerve cells make muscles tense or loosen (see graph). In ALS patients, these nerve cells responsible for the muscular system, called motoneurons, degenerate inexorably. As a result, the patients are increasingly paralyzed. The last possibility to stay in contact with other people is often the eye muscles: Patients learn to answer yes-no questions with eye movements or to control a computer.

Illustration: Rugar Benedikt

-•

LIS: Locked-in Syndrome

Several diseases can lead to a state of almost complete paralysis. ALS is one of them. Unlike a persistent vegetative state, Locked-in syndrome is a state of consciousness in which the sensory organs perceive the environment. Patients can, however, communicate at most via eye movements, eyelid twitching or grunting. In recent years, an EEG cap with a computer has been developed for these patients that translates their brain activity into letters.

Illustration: Rugar Benedikt

-•

CLIS: Completely Locked-in Syndrome

In this state, patients have lost all control over their body, even over their eye muscles. Contact via EEG caps also fails. The extent to which a person's brain is still working in the CLIS state is controversial.

Illustration: Rugar Benedikt

-•

BCI: Brain Computer Interface

The technique called "brain-computer interface" is an apparatus that connects a human brain directly to a computer. Among other things, it is used to facilitate mobility and communication for people who no longer have control over their language and muscles. BCIs can be used to control prostheses or wheelchairs, for example. But the technology can also help to spell. Selecting letters using an EEG cap that measures brain waves works amazingly well. As soon as the desired letter appears on a screen, people should think of a dance, for example, and the BCI recognizes this signal.

Photo: Nadio Verlyck/Wyss Center/dpa/picture alliance

-•

NIRS: Near Infrared Spectroscopy

In addition to recording the electrical activity of the brain using EEG, the measurement of the blood flow in brain convolutions offers another opportunity to decipher the thought process. Small infrared light sources shine through the skull bone into the brain, while sensors measure the scattered light. The signals show how strongly brain areas are supplied with oxygen. In "functional near-infrared spectroscopy" (fNIRS), blood saturation can be monitored during various thought processes with a cap full of sensors.

Illustration: Rugar Benedikt

Previous image 1/5 Next image

Birbaumer did not want to accept that he could not penetrate to the trapped ones. That he did not know how they think. There had to be something else. He set out to search for eleven years.

So he came to the Faehnrichs.

The professor found in Waltraut Faehnrich, not long gone but ungraspable, the ideal patient to prove that even the thoughts of completely enclosed people can be deciphered. Maybe it's just too exhausting for people like Faehnrich to even think whole sentences purposefully? Birbaumer wanted to go deeper into the brain, where the thoughts originate. He put a neoprene cap on Faehnrich, which was studded with sensors and connected to a laptop - a "Brain Computer Interface", BCI. The blood circulation of the brain is measured by means of infrared (NIRS). The idea is that different thoughts produce certain blood circulation patterns, that a yes looks different than a no. [P]  
[SEP]

"Hamburg is on the Elbe."

"Berlin is the capital of Spain."

"You're sitting in a Porsche right now."

Birbaumer and his colleagues Waltraut Faehnrich asked such questions. After 15 seconds the result from the speakers of the special computer quaked: "Your answer was recognized as no", "Your answer was recognized as yes".

Joachim Faehnrich asked his wife more personal questions.

"Do you have pain?"

"Do you like it when the kids come to visit?"

"Is Storm of Love your favorite series?"

For months, Birbaumer tried out the technology until he saw a quota of more than seventy percent as correctly recognized answers and believed he could present samples that were strong enough to convince the experts: "There was something. Someone. Waltraut Faehnrich, he believed, spoke to them.

In 2014, Birbaumer and his colleagues published a scientific essay in the Journal Neurology about Waltraut Faehnrich and his success in bringing her mind back to light after years of darkness. He also published videos of his experiments with her, showing him standing with Joachim Faehnrich in front of Waltraut Faehnrich and joking. Birbaumer says in the film: "We are showing this in Hollywood."

Joachim Faehnrich wanted such a device at home so that he could communicate with his wife in everyday life. But the cap, hardware and software cost around 40,000 euros - which her health insurance company was not prepared to pay. The Faehnrichs went to the Hamburg Social Court, where the case was heard in October 2015. As proof of the effectiveness of the machine, a television report about the Faehnrichs was recorded in which Birbaumer had his say. There are also two scientific essays in the case files, both written by Birbaumer. The only witness who was summoned was Birbaumer: Niels Birbaumer, who emphasized in court that his technique recognizes "whether a patient thinks yes or no". The court was convinced. The health insurance company had to pay for the device. A success that means that other patients could now also access such devices more easily.

For the Faehnrichs, the professor is a miracle.

For the professor, the Faehnrichs are a gift.

Two years later, in the spring of 2017, another article by Birbaumer's team appeared in the US journal PLOS Biology, which gave the professor a new nickname: the mind reader. In the study, Birbaumer also described the system tested on Waltraut Faehrich in three other patients. The publication was intended to prove this: The method is still valid, the blood circulation in the brain looks different for each patient - sometimes a yes is a sharp curve in the graphic representation, sometimes it looks like a wave - but Birbaumer was sure he could read from it what was going on in the patient's head. For Birbaumer, who is used to fame and recognition, the essay on the new method was probably his greatest success - at least in terms of attention. More than 80,000 times the paper was called up on the journal's website, ten times more than most other texts there. Countless press articles and television programs all over the world reported. The British newspaper The Guardian wrote of a "groundbreaking system". Through the Deutsche Presse-Agentur (German Press Agency), a report was circulated that was picked up in newspapers across Germany that wrote: "Headgear can read thoughts of completely paralyzed people".

Birbaumer was convinced in many interviews that he had finally made contact with people who basically consist only of their brains: "They are mentally awake. We have to read their minds. In another essay, Birbaumer described the "satisfactory communication results": Thanks to his research, patients with ALS-CLIS would no longer have to experience a "completely trapped state" in the late stages.

The professor, caught up in the search for the thoughts of the prisoners in the meantime, finally believed himself and his patients to be liberated.

Spüler thought: "There's something fishy."

On 9 October 2017, eight months after the celebrated release, Birbaumer received an e-mail. The sender was a computer scientist named Martin Spüler. Birbaumer knew him, Spüler, 35 years old, helped since his study days in Tübingen with the evaluation of brain data and was called Birbaumer in several publications as a co-author. In the meantime, Spüler headed a working group at the Institute of Computer Science, ten minutes away from Birbaumer's Institute by bicycle.

Spüler had taken a closer look at the figures in Birbaumer's groundbreaking essay. He actually only wanted to test a program that could improve data evaluation in future publications. Spüler was also fascinated by the idea of helping completely paralyzed people. When he was a student, he once stood at the bed of such a patient, and he has not forgotten these impressions. Now he fed the data into his program - and out came data garbage. Something was wrong. So Spüler began to recalculate the statistical evaluation of the essay. He came to no useful result. Today he remembers that he thought: "Wow, if that were wrong."

He speaks slowly and with the soft tongue of a person who has lived for a long time in southwestern Germany. Had he miscalculated? He checked again and again, but his findings remained: In contrast to Birbaumer, he did not come to the conclusion that the numbers were an answer to the question of which thoughts were paralyzed. Rather, for him there is no answer at all in the data.

He inquired. Spüler asked for a meeting with Ujwal Chaudhary, co-author of the article by Birbaumer and in his team responsible for the details, the calculations and the data collection. They know each other. The tone was friendly, Spüler remembers. It could still have been an accident. But Chaudhary



could not eliminate the doubts. "When we sat together in front of the computer, it became clear to me that something was wrong," says Spüler today.

He began to summarize his doubts in a report, he sat for several days in front of his screen, which today has a sticky note reminding him to water the houseplants regularly. Spüler documented all the calculation steps and inconsistencies. He wrote the mail to Birbaumer and attached the twelve-page report: "I have the problem that I cannot reproduce the results. I hope you take my report seriously and try to disprove me." And for the first time, Spüler wrote the sentence that has since become the leitmotif of his work: "I don't think there is any evidence of NIRS-based communication with CLIS patients".

The e-mails show how Birbaumers working group reacted to the accusations. She had a young doctoral student from Brazil do the math. The doctoral student confirmed Spüler's criticism and stated: "Unfortunately, I also have the impression that the results could be wrong. Birbaumer replied: "If that were true, it would be sad for the patients".

A week later, Spüler received an answer from Chaudhary. He wrote: "I have read your report and decided not to write a report explaining our approach, as most of your doubts are that you lack knowledge about our experiment and how NIRS works in the first place".

With this mail, Spüler remembers today, his hope of peacefully resolving the matter has died. Why did his colleague accuse him of ignorance when he had only pointed out statistical problems? And why did Birbaumer's team not want to correct the statistics? The deeper he dug, the harder his suspicions became. Not only that, in his opinion, data had been misinterpreted. He also noticed that central data was missing in the publication.

The Brazilian doctoral student, according to the University of Tübingen, left Birbaumer's research group shortly after he had confirmed Spüler's comments. Today, the man lives and works in São Paulo; he does not want to comment on his farewell from Tübingen and writes that he hopes for an academic clarification of the processes.

Spüler then decided to make his doubts public and expressed his intention to submit them in the same journal in which Birbaumer's study had been published. According to Spüler, Birbaumer gave him the impression that his critical essay had no chance there.

Martin Spüler reports on several meetings with Birbaumer's working group, one of which had left Birbaumer with the words: "Children, I've had enough of this". Spüler says that he himself then went home by bicycle, it was late, but he was too agitated to eat or sleep. He walked through the fields that begin just behind his apartment, living alone on the outskirts of town.

Spüler published his reply on bioRxiv.org, a publicly accessible Internet server for manuscripts not yet reviewed. But the attention remained missing. Spüler writes a bit awkwardly, his criticism did not sound very professional. He was also concerned with complex statistical questions, with the order of averaging, with hyperparameters. Only the headline was brash: No reference to communication with CLIS patients.

Meanwhile, Niels Birbaumer let himself be celebrated for his success. Several times he demonstrated to journalists in the family circle of patients how he allegedly communicated with completely

paralyzed patients via yes-no questions. During this time, a multi-page report entitled "Can he read minds? A reporter from the Süddeutsche Zeitung also accompanied Birbaumer to a locked-in patient.

If Birbaumer's findings were so trend-setting, so sensational, why didn't he put them on the big stage in the professional world?

No journalist asked why such a sensational paper had been published in PLOS Biology, a non-clinical journal that otherwise deals with intestinal bacteria and butterfly genomes. In addition, PLOS Biology is considered to be the lower middle class by the specialist journals. The impact factor, the common measure of importance, is nine. A top title like Nature has an impact factor of 41. If Birbaumer's findings were so groundbreaking, so sensational, why didn't he put them on the big stage among experts?

Our demands in the world of science are initially met with restraint. They would like to deal with the matter internally. It is only gradually that something frightening comes to light: the affair is widely known among experts. In seminar rooms and conference corridors, Birbaum's study and his offensive approach to patients are intensively discussed. There is mocking talk of Birbaumers "magic machine". "The community is boiling," says a BCI expert. A high-ranking colleague says that Birbaumer has "totally lost it". Another speaks of "stubbornness in old age". Nobody wants to be named by name. That is dangerous, even those say, who are no longer dependent on the goodwill of the famous pioneer in their field. "We all know each other very well," explains one professor, "everyone is a reviewer of everyone. Birbaumer has a "huge reputation" and a lot of influence. In fact, Niels Birbaumer is for many a scientific foster father. For years he has been engaged in fantastic science, emphasize all the interviewees. But in the meantime he is unfortunately "on the way like Captain Ahab on the hunt for the white whale".

But how can his colleagues keep silent in public, while Birbaumer continues to care for patients and give hope to relatives, even though his method is more than questionable? Nobody doubts that Birbaumer himself is fully convinced that his brain cap works and that he can communicate with CLIS patients. But the only solid basis for this is his own publication of 2017, which, as all the experts surveyed confirm, is inadequate.

"I have used various test methods and could not find any statistically significant effects in the data," confirms a well-known colleague of Birbaumers on request. The statistician Fränzi Korner-Nievergelt from the Swiss statistics company Oikostat, commissioned by SZ-Magazin, also sees a clear indication that Birbaumers' 2017 work "suffers from pseudoreplication". In less academic terms, this means that the evaluation is practically worthless.

"In my opinion, the available studies are currently not robust enough to make any kind of statement about the communication skills or awareness of CLIS ALS patients," explains a BCI data expert. In his opinion, Birbaumers publication does not stand up to careful scrutiny and should be withdrawn. Measurements by a Korean working group recently even suggested that the brains of CLIS patients are turning into a kind of twilight state over time. Another BCI expert demands that Birbaumers "casual handling" of data must be stopped. But this colleague of Birbaumers also wants to remain anonymous. Nobody wants to experience for themselves what Martin Spüler went through. One who has known Birbaumer for a long time quotes the metaphor of the king, who can only be brought down when the first blow is in place.

Unperturbed by such discussions, Niels Birbaumer travels from trapped patient to trapped patient, from Grimma in Saxony to Italy, currently caring for ten families.

Birbaumer has a small apartment in Venice, but he is hardly there. Since he was emeritus in Tübingen, where he still has an office, he has spent most of his time researching in Geneva, financed by the Wyss Center, the foundation of Swiss billionaire Hansjörg Wyss. In addition to an adult son, Birbaumer has two smaller children who grow up with their mother in Berlin. Birbaumer visits them every four weeks, and they come to him on holiday. He then takes them to his patients, because he doesn't have any holidays himself. Children, he says, are completely unproblematic in dealing with the motionless. In contrast to many of the employees he has had in recent years.

On a Saturday in March 2019, a young Italian scientist, only socks on his feet, squats in front of his laptop on the floor next to the bed of Felix S., a Locked-in patient from Ebersberg near Munich. Birbaumer nests at the video camera with which he is recording the question session today and gives some instructions in Italian.

He doesn't get any German scientists anymore. For them it was too stressful, the travelling, the suffering in the families. He can only get Indians and Italians "because they can't find work," says Birbaumer, and a Russian woman also helps out: "If I know that they're poor, then I know I'll hire them. He knows how bad it is to have no money. He stays. I don't need that kind of talent, I need engineers. I also need psychologists, but I don't get them, because they're only women, and they freak out after two times. They want to go home to their family in the evening, they don't want to sit there."

So Birbaumer is primarily responsible for communicating with his relatives, who usually don't understand his employees at all. They take care of the technology, of ensuring that the connection with the patients functions technically.

Felix S. is 33 years old, four years ago he got the diagnosis ALS, young, strong, athletic. In the first summer, he was still sitting in a wheelchair when his friends came to grill. But it all happened so quickly, says his wife, Lena S. A week before his son was born, two and a half years ago, her husband spoke for the last time. When the little one comes home today from kindergarten to the bright new apartment, where toys are mixed with medical equipment, she first leaves him with his dad, he is very careful when he climbs on him. Before that, Lena S. types a few more questions into the speech computer that Felix used to control with his eye movements. Questions that her husband can no longer ask. "How was kindergarten, my darling?" The son then talks about the world out there that Felix S. can't experience. For the son, the computer voice is that of the father.

Lena S. was in contact with many self-help groups and experts. Nobody could help her, such a rapid course of illness is rare. Her sister-in-law finally told her about the article in the Zeit about the professor who can read thoughts. They sent a video of Felix S. to Birbaumer and drove to Tübingen. Birbaumer's waiting list is long and he rejects many patients. But Felix S., he knew that from the start, had only just disappeared completely, with a robust body, and was a promising patient. Birbaumer has been coming to Ebersberg for a year now.

When he waits at the patient's bed this afternoon, when the Italian employee has to restart the computer program, Lena S. points to Niels Birbaumer and says: "There she is, our last hope".

Birbaumer worked with EEG again at Felix S. from the beginning, the infrared cap had not worked with him. In the past few months, communication has worked well, says Birbaumer. But S. now answers many of the standard questions incorrectly.

Lena S. says she can still tell how he is doing and what he wants by the twitching of her husband's eyes. Felix S., says Niels Birbaumer, is on the verge of being completely enclosed, perhaps he already is.

Birbaumer plans to implant microelectrodes into his patients' brains as soon as possible.

Birbaumer takes a break at a nearby bakery. He notices that Lena S. is nervous because it doesn't really work out today with the mind reading. But that doesn't discourage him. He is one step ahead again, mentally ahead of everyone else. Birbaumer wants to have microelectrodes implanted in his patients' brains as soon as possible, which could also be the salvation for Felix S., perhaps this year, Birbaumer says. The Wyss Center is supporting him with several million euros. Implantation is "the only sensible solution in the long term," says Birbaumer, not this "fiddling around" with the brain caps and their sensors, which are constantly shifting. Nevertheless, his work on these brain caps is regarded as so groundbreaking that the Federal Ministry of Education and Research is subsidising the further development of his studies with over 1.1 million euros. The money was approved shortly after the publication of Birbaumer's doubted publication.

The professor is tired. "I've already said I'll quit soon," he says, "I've had enough, I can't bear it physically either." The only problem, he says, is that nobody else cares about the completely locked-in patients but him. The doctors didn't send anyone. Patients with whom he had success often died due to incorrect care or nursing staff who did not understand them, if he had been away for a long time, Birbaumer says. And the other scientists would not continue what he had started. They only envied his success. He cannot stop. The professor seems lonely in his fight.

Martin Spüler also continued to fight, alone. The attempt to publish his reply in PLOS Biology failed at first. One of the scientific experts did not find the calculations of Spüler convincing and expressed the concern that the matter could cast a bad light on the entire field of research. One asks for understanding. But then something strange happens: Birbaumer's much-noticed essay in PLOS Biology, accessible online, gets an erratum. The name of the Academic Editor, the technical sponsor of the publication, is exchanged. Suddenly it is no longer Nick Ramsey, a luminary and vice president of the international BCI Society, but a US neurologist named Karunesh Ganguly. Ganguly does not respond to inquiries. Nick Ramsey explains to SZ-Magazin that naming his name was a mistake and that he didn't even know Birbaumer's paper before it was published. Is he of the opinion that the communication with CLIS patients described there works? "I wouldn't bet my money on it," says Ramsey. This had been announced "too enthusiastically". "I don't think the results of the paper justify all the claims made." The method is not suitable for use in patients at home.

On March 23, 2018, Martin Spüler wrote a letter to PLOS Biology contesting the decision not to publish his essay. The reviewers are biased, presumably known to Birbaumer, that an objective review of his essay, which disproves Birbaumer's important paper, is not possible. Spüler wrote: "The question of whether communication is possible in the completely locked-in state is of great importance for patients, families and caregivers.

Spüler spent a total of 18 months publishing his response on PLOS Biology. Only when a third expert, anonymous as usual by the PLOS editorial staff, who supports Spüler's criticism with clear words comes into play, does the journal feel compelled to accept Spüler's article, and publication is announced for April 2019.

When Birbaumer learns that Spüler's refutation will be published, he continues to refuse to withdraw his 2017 paper. This would probably have ended the story somewhat lightly. Instead Birbaumer writes long replies to PLOS Biology, which are available to SZ-Magazin. One expert describes them as "deeply confusing".

Spüler now decides to submit an official complaint to his university. He writes to the ombudswoman and asks for an appointment. She had found Spüler's arguments convincing, he reports. She refers him directly to the dean of his faculty. Deans are among the most powerful figures in university life, they decide on the progress of young scientists, their veto can break careers. At the University of Tübingen, the accusation is circulating that the Dean of the Faculty of Mathematics and Natural Sciences, who is well known to Niels Birbaumer, Martin Spüler's superior, put Spüler under pressure. He is said to have told him that Spüler's career would soon be over if he continued to pursue his accusations against Birbaumer. In response to a request from SZ-Magazin to the dean, a university spokesman responds with a written statement in which he explains that the university is currently having these allegations "examined under disciplinary law", but that the accused "rejects all allegations of undue influence" against the university.

Formal proceedings were initiated at the University of Tübingen against Birbaumer on suspicion of scientific misconduct.

Spüler has been in contact with SZ-Magazin for several weeks now. At first, the accusations sounded outrageous. Too often, disappointed researchers who feel treated unfairly by their superiors come forward.

However, our research shows that things are already escalating behind the walls of the scientific establishment: The University of Tübingen has initiated formal proceedings against Birbaumer on suspicion of scientific misconduct. It is the worst accusation that can be made against a researcher. Birbaumer and his colleague Ujwal Chaudhary, main author of the PLOS Biology study in question, were questioned by a commission in meetings lasting several hours. The accusations are also known to the most important donor of German science, the German Research Foundation (DFG). Their spokesperson confirmed on request that it would be examined whether there should be an investigation procedure against Birbaumer.

It is remarkable that since the appearance of the PLOS Biology study more than two years ago, which encountered doubts in expert circles from the outset, nobody wanted to lift the finger except the computer scientist Martin Spüler. The University of Tübingen is concerned that the award of the University of Excellence in 2012 might be shaken.

Birbaumers colleagues fear that the entire field of research worldwide, research at brain-computer interfaces, could suffer damage because of this story. How can it be argued that a good reputation is more important than the discovery of scientific misconduct? Do a researcher's name and rank outweigh the quality and cleanliness of his work? Eminence instead of evidence - this often funny phrase from science would suddenly become bitter reality. The case of Birbaumer, this suspicion is

becoming apparent, is more than a strange individual case. It is the expression of a system error in the scientific world, where as many sensational publications as possible are the hardest currency - not least to obtain funding.

There are also colleagues from Birbaumer who do not want to speak openly of their doubts about his work because they are worried that Birbaumer's life's work might be discredited "only because he once made a fuss", as one puts it.

Fraud? Is this how it is called when relatives of CLIS patients believe it is possible to communicate with their loved ones? And: Was the "jewellery" around the famous paper from 2017 the only one? At least there was another unusual incident. When a colleague of Birbaumers, a doctoral student from Ecuador, wanted to submit his dissertation on the basis of the study on the first communication with Waltraut Faehnrich published in Neurology in 2014, experts from the University of Tübingen rejected the doctoral thesis. The shortcomings were serious. Enough for a sensation, too little for a doctorate?

Just a few days ago, a scientist told SZ-Magazin that further studies from Birbaumers research groups would contain conspicuous shortcomings in the analysis of data.

Birbaumer is brilliant in many respects, asserts a top German researcher who has known him for a long time, "but he always needs a corrective". Strong employees who put his sparkling ideas on a solid foundation. In recent years, this has become increasingly rare. Martin Spüler's perseverance is a "heroic act", a "David vs. Goliath fight" that could end in "scientific suicide for Spüler", says the scientist.

Six months ago, the University of Tübingen informed Martin Spüler that his contract would not be extended. Spüler has been unemployed since the beginning of April. He now wants to wait and see what the university's investigations show. And then decide whether he wants to continue working in science. Spüler never wanted his patients' imprisoned thoughts to become such a decisive topic for him. But now he has already spent a year and a half working intensively on it. And his doubts about a scientific study turned into his doubts about the scientific system.

Niels Birbaumer, experienced in dealing with journalists, agrees with a second, more detailed interview. Two weeks after the first meeting, he is back with Felix S. on March 25th. According to Birbaumer, he will soon be able to have microelectrodes placed directly in the brain of the first ALS-CLIS patient. It would be the finale of his work, a final step to convince all his opponents that he is right. We meet Birbaumer this Monday lunchtime in a trattoria in Ebersberg.

Birbaumer quickly gets to the point himself before we can address our research results: His paper in PLOS Biology had been "massively attacked", but he was not aware of any guilt. He calls his critics lazy, "they sit all day at the computer and stare into the screen". He had suggested that dishwashers should come to a patient. But Spüler only insisted on his statistics. The conversation becomes more tense when we go into the concrete mistakes that Birbaumer is accused of - the figures that do not support his theses, the missing data. It calls it "computer scientist skirmish". Martin Spüler had not been present at the data collection and therefore could not judge how well the system worked. "I don't care whether Mr. Spüler says that's right or not, because I know what's right and what's wrong with these data, because I was with most of them. The Commission of the University of Tübingen is not interested in him either, says Birbaumer. He does not want to withdraw his essay until he has

evidence "that something is really wrong". What would be evidence that would convince him? "If the Chaudhary had manipulated data. That may be so. I can't look him in the eye." Ujwal Chaudhary writes to SZ-Magazin on request that no data had been manipulated in the paper and that he therefore sees no reason to withdraw the publication.

Birbaumer says that the matter is "very close" to his colleague Chaudhary, who is responsible for the figures, but "it doesn't matter whether he miscalculated or not. One gets the impression again: Birbaumer believes that this is only about annoying details and that he is only interested in the really big questions. As he had said at the first meeting in Ebersberg: "I know where the thoughts come from. I know where I have to go! On this day he has to go and ask Felix S. questions.

The next day Niels Birbaumer writes a mail to the SZ magazine in which he suggests that Martin Spüler could have been bribed by "competitors", "Facebook" or "insurance companies". When asked, Spüler says: "There's absolutely nothing to it."

The physicist Stephen Hawking was one of the most prominent ALS patients. The disease broke out with him as early as the mid-sixties and accompanied him until his death in 2018. Hawking suffered from a rare variant of ALS, which runs slowly. With the help of equipment and a special wheelchair, Hawking was able to make his mark throughout his life.

Photo: dpa

Waltraut Faehnrich almost dies in March 2019. She is in intensive care for five weeks. A severe pneumonia. The day after her discharge from the hospital, Joachim Faehnrich drove his wife and a nurse to Florian Silbereisen's "Barclaycard Arena" in Hamburg for the big Schlagerfest, and from the seats for the handicapped one has the best view. It was funny, says Joachim Faehnrich. Because of Silbereisen's separation from Helene Fischer.

Joachim Faehnrich has not yet put the Birbaumer cap back on his wife. She must first recover. No unnecessary effort, if not just Schlagerfest is. The professor will visit again in April. Joachim Faehnrich has written down new questions to Waltraut that he received in the intensive care unit. Did you like the massage? Does your right shoulder still hurt? And it's time to ask her the hardest question again.

Would you like to go on living?

According to the computer, Waltraut Faehnrich had always answered yes. Should she say no one day, Joachim Faehnrich would inform a doctor. In his presence, he would put the cap on her again and ask her again. In the event that the voice from the computer says no again, Joachim Faehnrich thought everything over. The music. The light. The moment when the doctor, probably in the farewell room of a hospital, switches off the ventilator. 35 minutes then remain. His wife's death is two questions and 35 minutes away.

Joachim Faehnrich does not want to think about it. There is no life for him without Waltraut. Sometimes he feels closer to her than ever. Through this illness they have become one person, he says. Body and mind. It is as if they have no secrets from each other since his wife can no longer speak, says Joachim Faehnrich. What should he do without them? Only lying on the sofa? He does not look at the storm of love without Waltraut.

"Without the possibility to communicate our life would not be so fulfilled," says Faehnrich. He wants to pass on some of what he has learned over the past twelve years. Now, when he has a break from everyday ALS life, he answers the questions of relatives of ALS patients and cares for other Locked-in patients, he has also been trained as a death attendant. This disease has become an important part of his life because Waltraut has remained the most important part of his life.

Joachim Faehnrich calls the professor "Niels". Sometimes he scolds him on the phone when the computer goes on strike. But they have become friends. On the desktop of his computer, a picture can be seen showing the Faehnrichs with their nurses and Niels Birbaumer at the celebration of their Golden Wedding 2018 in Mölln. The professor gave a speech. In it Birbaumer says that Waltraut may have achieved the ancient "ideal" of the "Vita Contemplativa," "thinking and feeling without a particular purpose or wish fulfilment. Niels had also shown this with his surveys of completely locked-in patients, says Joachim Faehnrich: "Their life satisfaction is high.

What does Joachim Faehnrich say about the fact that there are scientists who doubt that Niels Birbaumer's miracle computer works?

"I don't care at all about that," says Faehnrich. "They can calculate as much as they want. I know it works. I'm the only one who can judge that because I'm the only one who has such a device at home."

Hope and will are all that remains for the husband. And everything he needs. Nor does the professor have more than hope and will.

Only: he would need more.

-•

Patrick Bauer

-•

Patrick Illinger

-•

Till Krause

The contact to Martin Spüler was established at an annual meeting of the "Chaos Computer Club", at which the SZ magazine editor Krause gave a lecture and was approached by a colleague of Spüler. Together with Illinger, the head of the "Knowledge" section of the Süddeutsche Zeitung, and SZ-Magazin reporter Bauer, he researched all the background information. Informants can send him encrypted messages under the e-mail address: tkrause@sz-magazin.de (PGP: E2B83AE4).