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I Didn't Want to Go Bald. A Pill the Doctor Gave Me Destroyed My Life

A hair growth agent used by thousands of men in Germany leads to severe erectile problems. Patients are now filing lawsuits against the pharmaceutical company, which could write legal history

By Anne Kunze

Editor's note: This English translation was done by a third party. The original report can be accessed at [Zeit Online](#).

The night Thorben Weber* lost his manhood ended with, paradoxically, a stunning sunrise in front of his bedroom window. It was July 2015 when he drew his curtains open and looked out at the gently rolling hills of the Black Forest. His body looked the same as always. But nothing worked like it used to.

In the ensuing weeks, Weber lost his girlfriend, his apartment and his self-respect. When he describes how his misfortune began, it takes him a long time to find the right words. Finally, he blurts out, "I just couldn't get it up anymore."

Weber is convinced that this is due to a hair-loss medication. The drug is available in pharmacies under names such as Propecia, Finapil, and Finasteride-Ratiopharm. It's the world's largest selling hair-loss treatment. Tens of thousands of men take the pill in Germany; hundreds of thousands in the US; and, according to his doctor, even American President Donald Trump is a user.

Some of these men experience disturbing symptoms during and after discontinuation of the drug, such as erectile dysfunction, depression, concentration disorders, sleep disorders and many more.

There are over a thousand affected patients in Germany and tens of thousands in the US. Men all over the world have joined forces to file lawsuits against some of the companies that sell the hair restorer. Thorben Weber is one of them. He demands compensation from the pharmaceutical company Dermapharm, which manufactures a generic version, for damages and personal suffering. If Weber and his fellow combatants win their lawsuits, legal history could be written.

Weber couldn't have foreseen any of this when, back in July 2015, he intended to sleep with his former girlfriend one night, as he had done hundreds of times before. Suddenly his penis became flabby. That had never happened before, he says. He assumed it was caused by excess alcohol consumption. Even today, you can see the shame Weber feels when he talks about it.

A growing anxiety had now become the defining theme in his life. Today, at age 33, Weber is a broken man. He would have never imagined that taking a seemingly harmless pink pill for hair loss would have been so momentous. It never crossed his mind that a few pills could have the power to destroy his happiness. "I am isolated," he says.

Pre-Propecia, his life was vastly different; a cheerful young man, surrounded by other young people. He is a teacher of mathematics and music, an avid hang-glider pilot, a passionate drummer, the conductor of an orchestra, and the leader of several youth camps.

Many children liked him, he says. "I quickly found a connection to them." He has kept letters in which students thanked him for fun afternoons in the orchestra, and raved about the mountain bike tours that Weber had taken with them on school trips, when he was still feeling good.

Back then, he also approached women without any worries. He often spent his evenings in pubs and clubs in Freiburg. Women were drawn to his humor. When he talks about it today, something of that cheerfulness flares up. But just as quickly, his voice loses its spark. Weber, a gaunt young man with thinning hair, collapses. All his stories hinge on one discouraging word: "before."

Since losing his ability to have an erection, Weber discovered a connection that he didn't know existed: the link between a fulfilling sexuality and a successful life. The more one is missing, the more difficult the other one becomes. Today, Weber reflects on how much happiness depends on this seemingly small question: can it get up or not? Weber never thought about that before. Now he is afraid that others might find out about his disorder.

Weber remembers well the first time he slept with a girl as a teenager. It was very exciting. He and his friends were smirking about sex, wondering if they could make it work, but the truth is, none of them ever really doubted it. When the time came, Weber drank alcohol to muster his courage. It was a beautiful night, he remembers. He could rely on his penis even when he was drunk. After the first time, Weber experienced countless nights of carefree, exuberant sex.

But then, in July 2015, he noticed the worried face of his girlfriend. Out of consideration, she still tried to pretend nothing worrying had happened, but Weber sensed immediately what was going on. She stroked, lured and caressed him, but to no avail. Not that night, not the following one.

Lonely as hermits

From then on, Weber's thoughts centered on one question: How do I get an erection again? He ate Maca, a root that is said to be an aphrodisiac. He was prescribed Viagra by a urologist. He tried to masturbate at every opportunity. But nothing worked. Not with his girlfriend, not alone, not when watching porn videos, and not even with a fourfold dose of Viagra. "How can that be?" his girlfriend had asked him. "You're only 30 years old!"

Today, Weber describes the situation: "I felt lust, but I couldn't bring it up." The evenings were long and tormenting. Weber and his girlfriend were tiptoeing around each other, avoiding the question, When will we sleep together again? Soon they started changing clothes in the bathroom, in private, hardly seeing each other naked anymore, and eventually stopped touching each other at all. It went on like that for a couple of weeks, until his girlfriend left him.

Now she lives in another city and has a toddler. Weber, who always wanted children, has given up hope for a family. He would have to find a new girlfriend first.

But when should he tell a woman he meets that he can't get an erection? At the first kiss? Before that? No, he is too proud for that. The shame, the torment in bed, the pain of separation. He does not want to do all that again.

Weber no longer approaches women, and when someone shows interest, he rejects her. He feels unable to cope with the excitement, emotional stress and physical contact of a new relationship. Weber feels damaged. Dignity is something fragile and requires gestures of affirmation. His former girlfriend's words resonate in his mind: "You can't get it up anymore."

Meanwhile, his desire for sex has completely disappeared. Full set of hair, but no erections. It sounds like a bad joke. It sounds like a joke until you realize that one's life can be seriously damaged by impotence. "I didn't want to go bald. The pill the doctor gave me destroyed my life." Weber says.

Back when Weber was still a cheerful young man, he would flirt often. In the teacher's room, while playing sports on the weekends, while dancing at night; he usually found women who interested him. It was not always a relationship, but the vague possibility of getting to know a woman spurred him on.

Now he no longer goes out in the evenings. He no longer trains at the gym because he wonders, "Do I need a muscular body if no woman will ever see me naked again? Who am I doing this for?" In the past Weber often went to the movies. Now he lies on the sofa and watches series on Netflix.

He has only told his parents, his younger sister and a few friends about his condition. They cannot comprehend how bad Weber is really doing, and he cannot understand that others are dealing with problems that seem so small: like a cold or an argument in the office.

His friends already have partners or wives; some have built houses and started families. Weber has secluded himself more and more to the point where his friends hardly contact him. Perhaps the misery that Weber radiates is too much for them.

All men who suffer from erectile dysfunction caused by finasteride will tell you very similar stories:

A former lawyer from Frankfurt am Main, who once worked for clients from all over the world. Today walks crouched like an old man. At just 34, his career is over.

A businessman from Dusseldorf still manages a department with 50 people, but no longer dares to speak in front of his employees.

Mark Müller, a graphic designer from Leipzig, once had so much sex drive that he made appointments on the Internet to meet up even at lunch breaks. Now he says, "I used to be such a lustful person, now I am just dull."

None of them is older than 35. They all live lonely lives, like hermits. They are men, starting to go bald, outwardly unremarkable, inwardly ragged. They are all pale figures who have come together to file a lawsuit against pharmaceutical companies. A sad army of the listless has arisen, ready for their last battle.

A fog in the head

Back in October 2013, Weber deliberately combed his hair to cover his forehead. His receding hairline bothered him, so he went to see a dermatologist. "Do you also do hair transplants?" he asked. "No," the doctor replied, "but there is a pill that works very well, a remedy with finasteride as its active ingredient."

This is how Weber remembers the conversation: The doctor didn't mention any side effects. He talked about the pills as if they were Smarties. Weber was quite satisfied with the product. His hair was growing again, though not as strong as he hoped.

To understand how this drug works, we must go back to the 1970s, when a young hormone researcher traveled to the Dominican Republic, to a remote village called Salinas. There lived 24 "male pseudo-hermaphrodites," as she called them. They were boys with penises and testicles so small that at birth they were thought to be girls and were raised as such. At puberty, their genitals grew and their bodies became muscular. The villagers realized the once-considered girls were actually boys, and dubbed them "guevedoce," which means "penis at twelve."

The scientist found out that these boys lack an enzyme that turns the male sex hormone testosterone into a much stronger hormone, dihydrotestosterone. This super hormone also affects genital growth in males. In the case of the guevedoces, only a hormone boost of the less effective testosterone in puberty leads to the delayed formation of their genitals.

One particular phrase in the scientist's report got the attention of the chief of the US pharmaceutical company Merck & Co Inc.: The older guevedoces have an unusually small prostate and a full set of hair. What a message! Millions of men suffer from hair loss. In the 1980s, Merck developed an active ingredient that blocks the same enzyme that converts testosterone into

the super hormone dihydrotestosterone. That would turn men who took the drug into guevedoces, causing a kind of retroactive effect. It obviously works.

In 1992, Merck launched the pill in the US as a drug for older men with enlarged prostates. Nobody seemed to care that some of these patients reported erectile dysfunction after the use. In 1997, Propecia was introduced, a pill for hair loss that contained the key ingredient in a lower dose – but apparently still enough to permanently prevent erections after discontinuation and cause a considerable negative impact on the libido.

The young men didn't know about this fact when they took the pill. It was not written in the patient information leaflet. The only thing they were worried about was being bald. From 1999 on, the pill was also prescribed in Germany. It has been hailed in the media as "The hope for bald heads," "joy of living from the lab," and even as "Viagra for the scalp." In 2017, 120,000 packs of the hair product were sold in German pharmacies by prescription, plus a number of packs were ordered over the Internet.

The court will go to the root of these questions. When exactly, which side effects were known, to whom and whether the drug companies warned patients clearly enough or not. Patients took either Propecia, the original pill of the German Merck subsidiary firm MSD, or Finapil, the generic drug manufactured by Dermapharm.

When Weber started to take the hair wonder medication more than four years ago, he read in the leaflet that "occasional" potency disorders might appear. In fact, Weber noticed then that his lust for sex eased a little. This prompted him to discontinue the remedy after one and a half years. A little later, he went through that unforgettable July night. The package leaflet also stated that potency disorders could occur "in unknown frequency" even after discontinuation of the drug. "Unknown frequency, I didn't know what that meant exactly," says Weber. "And the real stunner was yet to come."

The real stunner reared its head in the form of so-called "brain fog," which afflicted Weber. It made him perceive colors as faded, and contrasts in his environment grew blurry. Weber was looking at his life as if through frosted glass. He was feeling disconnected from the world, and suddenly started forgetting names of students he had taught for years. Weber, the math teacher, was standing in the classroom in front of the blackboard, no longer understanding his own tasks. $12 + 5 \div 6$, first the division, then the addition? How did that work again?

When entering a supermarket, he forgot what brought him there in the first place. He no longer dared to go by car into the mountains, fearing he would not be able to find his way back. Gradually, he sold his musical instruments, because nothing was giving him pleasure anymore. At night, fear crept over his chest and hissed at him like a wild animal. That is how he describes it.

On some days, Weber felt so exhausted that even the few steps in the school building were too much to take. His face was pale and the colleagues in the staff room had already begun to whisper about him. Were they thinking he was taking drugs?

His penis, Weber says, felt very small, numb and cold.

The 'Mood-Killer Syndrome'

A year ago, Weber was no longer able to shop for groceries or even to do his own cleaning, so he gave up his apartment and moved back in with his parents to live in his old room. For weeks, he couldn't go to work. One day he wrote down on a piece of paper that his younger sister should get his Audi A3 and his best friend his electric piano. He scouted out a spot on the railroad embankment, where the track can be easily reached and the trains go too fast to break.

"You have depression," his family doctor told him. "But what about the erectile dysfunction?" Weber asked. "The foginess in the head? The concentration dysfunction? The sleep disorders?"

Neurologists, urologists, dermatologists... they all said Weber was just imagining the discomfort. It took weeks before a professor of andrology at Münster University Hospital made a diagnosis that could explain all the symptoms. "You have the Post-Finasteride Syndrome," said Michael Zitzmann, a specialist in hormones and men's diseases.

This syndrome, according to the professor, is a bundle of symptoms that appear after patients take the hair remedy. The professor spoke of the "Mood-Killer Syndrome," which is not mentioned in the leaflets. It is often irreversible. For some of the approximately 100 patients that the doctor has examined so far, it went better after some time, but most need to be prepared to be permanently damaged in body and soul.

"Using Finasteride for hair loss is like shooting at sparrows with cannons," says the professor. "The drug interferes massively with the hormonal balance. It blocks not only the super hormone but also other hormones that affect thinking and psyche, mood and emotions. Discontinuation of the drug should actually make the hormones work again. Everything should go back to normal but apparently, something completely breaks down in some men, as well as in the prostate, in the brain, in the whole organism. What exactly, is not clear. That's why there's still no therapy."

A spokeswoman for MSD, the German subsidiary of the pharmaceutical company Merck, says: "In our opinion, there is no reliable scientific evidence for the existence of Post-Finasteride Syndrome." The manufacturer of the generic form of the drug, Dermapharm, did not want to comment on repeated requests from the ZEIT.

The pharmaceutical companies would most likely know best how many and what side effects their drug causes. For the market launch of the drug, controlled trials on subjects had to be performed. It is questionable how reputable they were. For example, a 1991 study protocol that was published shows that some men had mental health problems while taking the drug – three times as many as in the placebo group. However, the people in charge at Merck thought that the psychological problems had nothing to do with the tested drug.

An international team of independent physicians has analyzed the experimental protocols from 34 clinical studies on the safety of the hair remedy. Result: serious deficiencies. According to the analysis, the required quality criteria were not met in the protocols. In particular, the side effects and long-term consequences are hardly mentioned. More than half of the studies were at least co-financed by Merck itself. This is common in the industry. Two-thirds of all studies lasted only one year or less – an extremely short time.

In the database of the US and European Agency for the Evaluation of Medicinal Products as well as the database of the World Health Organization, numerous side effects and adverse reactions were reported by physicians or patients after taking Finasteride. However, too many health issues are still not recorded. Doctors are required by professional ethics but not by law to report them. Physicians and patients must first recognize a side effect as such. This is especially difficult with a complex drug that interferes with the hormonal balance.

Three years ago, scientists worked on a project on patient safety and evaluated the reports of side effects that occurred between 1998 and 2013 after the use of the hair drug. This was reported to the US Food and Drug Administration. In those years, approximately 15,500 adverse effects were documented, ranging from persistent sexual dysfunction, muscular dystrophy, breast growth and cognitive impairment to suicidal thoughts.

The researchers investigated only the results reported by men between 18 and 45 years. They noticed that nearly 90 percent of those at risk of suicide also reported sexual disorders. A connection was obvious. For the scientists, it was not only proof, but a clear indication of the Mood-Killer syndrome.

An industrially generated stroke of fate

Today, the database of the US Food and Drug Administration lists around 1,700 cases of depression after taking the Mood-Killer drug. One hundred and six people have killed themselves. The European Medicines Agency's database lists 48 suicides committed by people who took Finasteride. The results only provide information about a temporal coherence, not on whether the Mood-Killer drug was also the cause of the men's intention to kill themselves.

Weber has often thought about killing himself. He looked closely at the railway embankment close to where he lived but never laid down on the tracks. How would his parents and his sister react when they would find out about his suicide? Wouldn't he be destroying their lives as well?

That is the reason Weber drags himself through life.

But couldn't it be possible that the Mood-Killer had such an impact because Weber might have had a hidden previous inclination to sadness? That the drug merely reinforced something that had long existed in him? And that this was the case for many of those affected people?

It is possible that Weber and the other men who fell into severe depression, might have remained in mild depression if they wouldn't have been otherwise inclined, but one cannot imagine this is the case with erectile dysfunction.

It is undeniable that their lives would be better, so much better if they wouldn't have taken the hair loss pill. Is there somewhere a healthy man who isn't interested in sexual intercourse? To find such a man, you'd have to search for a long time. He may not even exist. That explains the serious effect this situation has on men, an industrially produced stroke of fate.

These men turned to a doctor out of vanity, not because they sought help for a disease, but because they did not want to go bald. Some of them did not read the leaflet carefully, but the doctors were apparently negligent as well. "They treat the prescription less seriously than with other medications because hair loss is rarely a medical problem," says Bremen's health scientist Gerd Glaeske.

The Federal Institute for Drugs and Medical products should be the one to take action and request the doctors in Germany today to better educate their patients. They did when it came to thrombosis risks in new birth control pills. Doctors were sent checklists that they should pass onto their patients. "But often the authority reacts too slowly and not in the interests of consumer protection," says health scientist Glaeske. "The institute actually has many options, but they just don't use them."

The Federal Institute must approve medication and can withdraw the permission of such drugs until it is clear what damage they can cause, but this option is rarely used. The Institute can also require that pharmaceutical companies conduct further studies or restrict the use of a product. It could be decreed that finasteride may only be prescribed as a remedy for an enlarged prostate, but not against hair loss. Why does the authority hesitate?

Thorben Weber sent a letter to the Federal Institute. He described his symptoms and what did the authority do? They didn't inform the doctors, didn't initiate a study, or denied that Mood-Killer syndrome exists. Thorben Weber only got a form letter as a response. It stated that the prescription of the magic hair cure is the responsibility of the respective doctor.

But it is the Federal Institute for Drugs that need to assess whether the benefits of a drug exceed its risks. That is exactly its purpose.

The Institute writes to ZEIT: "As long as patients seek medical advice and abort treatment if mental health issues occur, it continues to have a positive benefit-risk assessment when used properly." Due to this statement, the manufacturer MSD assures ZEIT, "the benefits of the drug outweigh its risks."

German authorities have since called upon the companies that make the hair remedy to check whether there is an accumulation of different problems after ingestion. Does this mean the industry can decide for itself whether Mood-Killer syndrome exists or not?

Weber and the other victims are fighting for the inclusion of this syndrome as a side effect in the package leaflet. Better yet, the drug should completely disappear from the market.

The Lawsuit of the listless

The lawsuit has great significance and that is the reason lawyers, doctors, and health insurance companies are so interested in the result of the legal complaint, which has been submitted this week at the Berlin district court by Weber's lawyer: Jörg Heynemann. Law is the foundation of society, and after the trial, many patients could be standing on a much safer foundation.

Until now, plaintive consumers in Germany had almost no chance against a pharmaceutical company. The few lawsuits that ever went to court failed, reaching settlements at best. A prime example is Vioxx case, an anti-rheumatic drug that was taken off the market because people died after taking it. However, complaints are regularly dismissed because there is always a stalemate: There can be no proof or refutation that there is a connection between a drug and a damaged patient. Even the biggest scandal in German's drug history, the Thalidomide case, ended in 1970 with only a settlement. That was mainly due to gaps in the law. The gaps have been closed since then.

Today, it seems, German law favors patients far more than it did in the past. It suffices that a drug can "potentially" cause harm to humans for a drug manufacturer to adhere to it. However, the highest German court, the Federal Court, considers this going too far. It states: Before a pharmaceutical company is liable for alleged damages, it must first be ruled out that no other cause is responsible for the damage. Was the person already ill before taking the drug? Then, according to the Federal Court, that previous disease could be the cause, and the manufacturer of the drug cannot be held accountable.

The lawsuit of the listless could change the situation right now, thanks to a powerful entity in Strasbourg.

In June of last year, the European Court of Justice reached a verdict that could considerably improve the patient's situation. European law takes precedence over national law, and Weber's lawyer Heynemann wants to use this verdict to get courts in Germany to be more considerate toward the patients. The lawsuit of the listless has become a test case.

The verdict of the European Court of Justice states: The patient no longer has to prove that there is a scientifically proven connection between a drug and a condition. It is sufficient if the court sees a connection between a drug and the illness of a patient on the basis of "serious, clear and consistent evidence" so that a drug company can be convicted.

There is a case of a Frenchman who was suffering from multiple sclerosis after a hepatitis B vaccine. There is no scientific evidence that the vaccine caused the disease. The European Court of Justice was satisfied with the timing of the illness after vaccination and the fact that no one in the man's family suffered from multiple sclerosis.

Transferred to the Lawsuit of the listless, this means: It is no longer crucial whether the Mood-Killer syndrome is proved beyond a doubt or not. The time sequence is important in this case, and also the accumulation of cases. If the German courts follow the European case law, the evidence of the side effects in Weber and the other affected patients after taking the hair-loss drug would be sufficient. Then MSD and Dermapharm would be liable for the consequences. Drug manufacturers need to be prepared to pay a lot of money for damages in the future, and the situation for people who become seriously ill after taking a drug would change significantly.

For people like Thorben Weber, it would be a glimmer of hope. Although winning the trial could not return Weber his happiness, it could restore a little bit of dignity.

BEHIND THE STORY

The challenge of research: When the author came across the topic, she wondered if a woman could even write competently about something that only affects men. She talked to several people and finally said to herself, "It does not help them to wait for a man to talk at length about their problems, because no one has done that yet.

More information: The endocrinologist Herbert Kuhl has researched the Mood-Killer Syndrome. He and his colleague Inka Wiegratz describe the result in the article "The Post-Finasteride Syndrome."

The active ingredient finasteride is offered by several manufacturers. The pills are available under prescription in pharmacies. A monthly package costs between 30 to 40 euros, depending on the manufacturer.

* The names of those affected and their circumstances have been changed for their protection