

*Editor's note: This English translation was done by a third party. The original print report can be accessed [here](#), and the original digital report [here](#).*

### **This is a fantastic remedy for baldness (but you might lose your masculinity)**

*The hair-loss remedy Propecia, which is taken by thousands of men in the Netherlands, can cause rare, but permanent, erection and ejaculation problems, and reduced libido. For this reason, the French drug-assessment agency ANSM sent a letter to 100,000 medical professionals this month, warning that Propecia (on the international market since 1997) can lead to sexual disorders that can persist after stopping the medication. The letter, which was distributed in Germany in comparable form last year, further warns about possible psychological side effects such as anxiety, depression and suicidal thoughts. Such a letter is not necessary in the Netherlands because the guidelines of the Nederlands Huisartsen Genootschap (Dutch General Practitioners Association) already clearly state what the side effects are, says the Medicines Evaluation Board. Within those guidelines, GPs are advised to exercise restraint when prescribing medication that combats androgenetic alopecia, the medical term for male pattern baldness, because "data on long-term efficacy and safety are limited or absent."*

### **By Irene de Zwaan**

About three years ago, Timo, 25, noticed that his hair was beginning to fall out. The process was gradual. "It wasn't that I stood in the bathroom after showering, with handfuls of hair in my hand. But my hands were fairly covered, and my hair got thinner."

While his friends were joking about it, Timo (who prefers to remain anonymous) increasingly wore a cap to camouflage his hair loss.

The meeting with Timo takes place in the Haarkabinet, a medical office in Tilburg with reflective floors and richly filled flower vases. Those who order tea will receive a bonbon. Here a solution is offered for androgenetic alopecia, a fancy word for male pattern baldness in which heredity factors play an important role.

To fight this form of hair loss, which affects half of the men by age 50, no caffeine shampoo, lotion or vitamin cure will help. The Haarkabinet has something else on offer: finasteride pills, sold under the brand name Propecia. It is known as the hair-loss agent with the best results.

Timo heard about it through an acquaintance who has been taking the pills for 18 years and has been able to keep his upper hairline. He advised him to start on time, now that he still has most of his hair. Finasteride works purely preventive, to prevent further hair loss. Men in whom baldness is already far advanced are too late.

"I think I'm too young to be bald," says Timo, as a friendly lady in a white coat sets him in the chair. With a microscopic photo session of his scalp the stage and further course of his baldness is determined. From so close, his hair looks like a few stray blades of grass in a lunar landscape.

### **Donald Trump**

Propecia, which originally came on the market as a medicine to help elderly men treat enlarged prostate, counts millions of users worldwide. Perhaps the most well-known is the American president Donald Trump, who, according to his personal physician, owes his bright blonde locks to the drug.

But taking it isn't without risk. About 1,500 men filed lawsuits against pharmaceutical giant Merck in the US. They argue that the manufacturer of the pills has long kept information about

permanent side effects from consumers.

Only in 2011, after Propecia had been on the market for 14 years—and American health authority FDA mandated it—did Merck state in the leaflet that use can lead to a persistent erection and ejaculation problems, and reduced libido. Men who suffered such symptoms let Merck know through their attorneys that they felt chemically castrated. They postponed their baldness, but permanently lost their masculinity.

In the Netherlands, 6,800 men took the hair-loss medication last year. Another 26,300 patients, according to figures from the Foundation for Pharmaceutical Statistics, used a similar drug that is stronger and more effective: dutasteride. It is sold under the brand name Avodart and is from another manufacturer.

Avodart, unlike Propecia, is not licensed as an anti-cancer agent, but only as a prostate medication. An unknown number of men (registration is missing), are prescribed the drug off-label to prevent hair loss. This means that it is provided to patients for an indication other than that for which it was intended. This practice has been under discussion in recent years, because safety can not be guaranteed.

Where clear guidelines apply to general practitioners and dermatologists when prescribing finasteride, the same are not available for dutasteride. It is generally assumed that the side effects of dutasteride are greater than those of finasteride.

Rob van Zandvoort, attending physician at the Haarkabinet in Tilburg, is therefore reluctant to prescribe dutasteride. For finasteride he dares to put his hand in the fire: side effects are extremely rare. “There is a small group” [EDITOR’S NOTE: one percent, according to the package insert] “that has had adverse responses to it, but it has not been proven 100 percent that this is due to the medicine.”

Van Zandvoort explains the effects of finasteride on the basis of a 3D model of a hair root. “The male hormone testosterone is converted at the hair root into the more powerful variant dihydrotestosterone (DHT), which causes the process of hair loss. Men who become bald are extra sensitive to this. The result is that they do not get new hair every four years, as usual, but every four months. Hairs are therefore becoming thinner and break down faster.”

Finasteride protects the hair root. The DHT levels in the body are reduced, causing hair to fall out less quickly. Anyone who wants a lasting effect must take the medication for his entire life. Cost: 500 euros per year.

“People are talking about it,” says Van Zandvoort. He knows men who have been taking finasteride for 20 years. His youngest patients are 16 years old. Hair loss has a significant impact on this group. Some have an inferiority complex or depression.

A bald head is a specter to many men, adds Steven Belknap, a researcher, associated with Northwestern University. But according to him, that is not yet a reason to thwart a natural aging process with pills “that no one can overlook the health risks.”

He refers to the lack of fundamental scientific research on Propecia. “Thirty-four clinical studies have been conducted on the drug. Not one of them can guarantee safety. Half of them have also been paid by the industry. The long-term effects are not known to anyone.”

In 2017, Belknap published the results of a study on finasteride and dutasteride users. Of the 15,634 men who previously had no sexual dysfunction, 699 developed erectile problems after taking the medication (4.5 percent), 210 men (1.3 percent) had a lower libido than before. Of the 103 young men (between 16 and 42 years old), 34 (33 percent) had permanent erection problems.

This assumes that Propecia has a greater effect on young than on older users. Not entirely illogical, since young people are sexually more active and therefore more focused on their sexual well-being.

Another striking finding: the young men who took finasteride or dutasteride for more than 205 days had a 4.9 times higher risk of developing permanent erectile dysfunction than men who used the drug for short periods.

Belknap's research was funded by the Post-Finasteride Syndrome Foundation (PFS Foundation), a US-based partnership between physicians and leading scientists. One of the goals is to raise money for independent research into the long-term effects of finasteride use. But with a clear mission: warn about the medicine.

Those who visit the PFS Foundation website are confronted with a number of alarming numbers from the database of the World Health Organization: 15,222 reports of side effects caused by finasteride worldwide, 59 users committed suicide and 33 made an attempt to do so.

"It's tragic that this product is on the market," says software developer John Santmann, who is also director of the PFS Foundation.

"Doctors prescribe a drug that completely disrupts the normal functioning of one of the most important hormones in the body (testosterone), expecting there to be no serious consequences for the patient. It's preposterous," Dr. Santmann continues. "And with that, a lot of money is generated for various players in the industry, which ultimately results in government agencies being lobbied away from taking a critical look at the situation."

The argument that side effects may not be the result of finasteride use, but of external factors, Santmann waves away. "We get hundreds of reports from men around the world whose lives have collapsed after taking finasteride. Their complaints are similar. That's no coincidence. It's damn hard evidence."

Santmann lives it up close. His son Randy, who struggled with depression after using finasteride, committed suicide at age 22.

"Look up the history of this drug," recommends Santmann. "That says enough."

### Girls with penises

The genesis of Propecia starts in the seventies, when the young American hormone scientist Julianne Imperato McGinley traveled to a remote village in the Dominican Republic. She had heard rumors about girls who gradually changed into boys.

Upon arrival, she found a group of men who had been born with such small penises and testicles that they were considered girls for their first years of life. Their true identity emerged during puberty, when their voices became lower, their bodies more muscular and their male genitals larger.

In a study published in *Science*, McGinley explained that the Guevedoces, as they are called (meaning: "testicles at 12"), lack an enzyme that converts testosterone into dihydrotestosterone, the male hormone that is crucial in the uterus for the development of the genitals in a male fetus. McGinley noticed something else: none of the Guevedoces was bald.

Pharmaceutical giant Merck responded to this observation. The genetic deficiency of the Guevedoces seemed to be a godsend for men with prostate problems—and for men with hair loss.

In 1993, finasteride came on the market, initially under the brand name Proscar. The pills of 5 mg each were designed to shrink prostates and help elderly men get rid of their urinary problems. The drug was an immediate success.

Four years later, the exact same drug was sold in the form of 1 mg pills, as a hair-loss medication. And so Propecia was born.

### Blurred complaints

In the family of Mark, 37, a successful international businessman, baldness does not occur. During our conversation with him, which takes place in a café with a view of an Amsterdam canal, his big head of hair immediately catches the eye.

More remarkable it is that he was prescribed Propecia when he went to see a dermatologist about hair loss stemming from a tropical disease. There would be no side effects, his doctor said. Mark should only stop if he wanted to conceive a child.

That warning is part of the standard protocol: there are indications that the genitals of a male fetus may show abnormalities if a woman becomes pregnant by someone who swallows finasteride. For that reason, the leaflet says, women are not allowed to touch crushed or broken pills during their pregnancy.

Not long after Mark (his real name is known to the editors) started taking the pills, he began expressing vague complaints: a nagging pain in his abdomen, pain in his scrotum, and a haze in his eyes. But the biggest change was that he slept badly: from eight hours a night to an average of two to three hours.

“I fell asleep, but then I woke up with a massive heartbeat, which I heard banging in my ear,” he says.

At first Mark did not relate this to his finasteride use. He visited various clinics, at home and abroad, hoping to find an explanation for his sudden sleep problem. An answer eluded him. One sleep expert advised him to see a psychologist.

“I was desperate,” says Mark. “My social life had dropped to zero, and I was struggling through my work days with difficulty.”

Through the Internet he came into contact with an American doctor who investigated side effects of finasteride. That doctor observed post-finasteride syndrome (PFS), a diagnosis later confirmed by Dutch neuropsychiatrist Marcel Waldinger.

“He said, don’t be fooled. It’s not between your ears. You have rare, but unpleasant side effects of taking finasteride,” says Mark. “It was a relief that someone finally recognized this.”

It has been eight years since Mark quit Propecia. The haze in his eyes has disappeared, as has the pain in his abdomen. But he says food allergies and an alcohol intolerance remain with him. And he still does not sleep as well as before. Yet he praises his plight. “I got off well. There are patients who have much worse side effects.”

“I’d like to make it clear that PFS is real,” says one ex-user of Propecia, who has serious depression that resulted from the medication. He does not feel like he is taken seriously. “I haven’t received any help from any doctor, not even from my own doctor—who pushed the drug on me.”

Thirty-year-old Serge Meulenberg from Sittard says that the medication, which he took for eight

years on the advice of his doctor, “slowly changed him from a healthy young man to an anxious and dejected person.” His libido declined noticeably. Panic attacks and depression later followed.

Ironically, Meulenberg advised his mother to take finasteride because she too was struggling with hair loss. But when she visited her doctor, she reacted with caution. The drug could cause depressive symptoms, the doctor told them. “Only then did I look over the current product insert. Turns out that it had been updated since finasteride was originally prescribed to me. I was shocked, and quickly quit that poison.”

### Vulnerable

Is finasteride the cause of these men’s complaints? Dermatologist Ids Boersma, who works at the Intermedica Kliniek in Boxmeer, is skeptical. Of the ten thousand patients he has treated with finasteride and dutasteride, in his own estimation only a few reported side effects. “But I prefer that to the placebo effect. Patients read about side effects in the package leaflet or on the Internet and then feel it spontaneously. I once had a patient with all the side effects from the leaflet.”

Willem Boellaard, urologist, andrologist and sexologist at Erasmus MC, does not exclude that the side effects are the result of finasteride use. But he does have one side note: men who are concerned about their hair loss—and about hair-loss medication—have a different psychological makeup than men who are less concerned about it. “This is a group of men who may be more vulnerable to uncertainty. That can go hand in hand with all kinds of complaints.”

In the Haarkabinet in Tilburg, Timo moves to Dr. Rob van Zandvoort. The results of the microscopic photo session and the blood test he has just undergone appear on the computer screen. He has 292 hairs per square centimeter. “That’s fairly normal,” says Van Zandvoort. But the results do not work. Finasteride is recommended. And Timo wants to know if there are any side effects.

“There can be,” says Van Zandvoort. “The advantage is that the side effects are gone within a week if you stop taking the medicine. It does not cause permanent damage.”

The doctor rattles over his keyboard. A moment later a prescription rolls out of his printer. “This is for three months. After that time, I’ll call you to see if everything’s going well. If that is the case, then we’ll continue.”

MSD (as Merck is called outside the US and Canada) states in response to this story that years of thorough research go into the effectiveness and safety of a drug before it comes on the market. This safety can only be guaranteed if “the right consumer uses it in the right way at the right time.” This is not the case with dutasteride prescribed for off-label.

### More than 400 reports

[Lareb, the Netherlands-based Pharmacovigilance Centre](#), has received 213 reports in recent years about finasteride users and 219 about dutasteride users. Most of the reports, which have been submitted by both patients and caregivers, are about patients who take the medication for prostate problems. Thirty-nine sexual side effects have been reported, such as impotence, reduced libido, reduced semen volume and erectile dysfunction.

### Only for “high levels of suffering”

The Dutch General Practitioners Association (NHG) advises GPs to prescribe finasteride for alopecia androgenetica, the medical term for male pattern baldness, only for “high levels of suffering.” “Long-term treatment is necessary to maintain the effect, but data on long-term

effectiveness and safety are limited or absent,” the guidelines state.

The NHG says in a response that it is not familiar with post-finasteride syndrome “as such,” but points out the possibility of permanent side effects, as described in its guidelines.