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Prescription Hair-loss Medication Propecia Accused of Ruining Lives

In June 2016, 25-year-old Romain took his life. According to his family, his death can be blamed on post-finasteride syndrome, named after the principal ingredient in this anti-hair-loss medication. Finasteride is sold by Merck & Co., which may now be subject to civil or criminal prosecution in France.

By Camélia Echchihab and Emre Sari

Editor's note: This English translation was done by a third party. The original French version can be accessed [here](#).

It was a routine appointment with the family dermatologist. Romain was 19 and his hair was thinning. "There's this super drug with no side effects. Everyone's taking it," said his doctor. Its name? Propecia, a medication made and distributed by American pharmaceutical giant Merck & Co.

In October 2010, Romain Mathieu began a daily regimen of the orange octagonal pills. He initially experienced periods of extreme fatigue, had trouble getting erections, and had difficulty falling asleep.

Six years later, he was completely impotent, vomited 15 times a day, did not sleep at all, and was losing his memory.

Romain killed himself on June 7, 2016, at age 25. In his suicide note, he wrote, "I will try to die with a smile, a final thumbing of my nose as I finally leave this illness behind."

Today there are hundreds of affidavits from men who have experienced hell, or at least a terrible ordeal. After having taken Propecia, or the many other medications whose active ingredient is finasteride, they complain of severe sexual dysfunction and cognitive and physical problems that continued even after they stopped the treatment.

They call their condition post-finasteride syndrome.

The illness, however, is not yet recognized as such. In the USA and Canada, nearly 2000 victims have come together to sue Merck & Co. (see below), which began selling Propecia in 1997.

Despite numerous alerts from health institutions in different countries, including France, as well as several worrisome changes in the mandatory product inserts (see below), in our country, finasteride is used in 23 generic drugs produced by 16 laboratories. Doctors, both GPs and specialists, prescribe it freely.

A box of 28 pills taken daily in 1 mg doses, Propecia sells for around 50 euros; the generic version for 15 to 20 euros. It is not reimbursed by French Social Security, and its efficacy – purely aesthetic – is limited. In the studies that accompanied the drug's 1999 entry into the market, patients claimed an increase of 11% in the amount of hair growing atop their heads; the drug's efficacy was not proven on the temples, but just above the forehead. And the hair fell out as soon as patients stopped the treatment. In addition, the study was only run for 24 months, precluding any conclusions about long-term effects. Finasteride, the active

ingredient in Propecia, has also been used since 1992 in dosages of 5 mg to relieve enlarged prostate.

In all, nearly 128,000 Frenchmen were exposed to the drug in 2016. The French National Agency for Medication and Health Products Security (ANSM) says 11,141,228 1-mg finasteride pills, and 35,617,456 5-mg pills, were sold in 2016.

A six-year battle

Sylviane and Marion, the mother and younger sister of Romain Mathieu, met us in an old building smelling slightly of mothballs, not far from the village of Orgeval (Yvelines). They moved to the Côte d'Or after Romain's suicide. Sylviane, 51, a brunette with a strong, determined presence, is warm, welcoming, often bursting into laughter.

Marion, 24, is somewhat quieter, often finishing her mother's sentences. The two of them tell us about their son and brother's six-year fight with PFS, which is still mostly ignored by mainstream medicine.

Toward the end of 2010, when Romain began having difficulties, the health professionals he saw were not worried. The young man was enrolled in a preparatory HEC class, an academically advanced option. "It's just stress," said his GP and his dermatologist, not addressing Romain's concerns. Romain had noticed his symptoms coming in longer, more intense waves. Sylviane, who accompanied him to all his medical appointments, remembers the names of all the doctors. "I did tell the doctors that Romain was taking a medication for hair loss, but not one doctor told us it wasn't a good idea."

Two years later, Romain freaked out, having noticed a hard lump in one of his breasts. The young man made an appointment at the Lariboisière Hospital in Paris. For the first time, he was prescribed several tests.

"I have the test results here somewhere," says his mother, who has filed all the prescriptions and test results in a huge binder on her dining room table. The results of those first tests were quite alarming: Romain had serious imbalances in his liver and spleen. He was deficient in proteins and Vitamin D. His testosterone level was 0.38 ng/mL, comparable to that of an impotent old man.

Several doctors saw these results and were concerned, but they didn't understand what they meant – and they didn't seem to want to understand, either. In the end it was a pharmacist who warned Sylviane when she brought in Romain's prescription to be filled. When she saw the word Propecia, she was surprised. "You're not giving this to your son, are you? There's a lot of controversy about this drug right now!"

Feeling worse and worse, Romain began scouring the Internet for information about this mysterious substance that might be the cause of all his suffering. He found a discussion forum, PropeciaHelp.com, and read accounts of the condition from many other sufferers. He recognized all the symptoms described by hundreds of men – and women – who were taking or had taken finasteride.

'It was sexual torture.'

In April 2013, Romain stopped taking the drug and his symptoms disappeared. He was relieved, felt he could breathe again. Unfortunately, the respite was short-lived. After two weeks, he began experiencing symptoms again, and they were much stronger – accompanied by new issues.

For this investigation we interviewed ten men who all mentioned the same sexual, physical and cognitive issues as Romain, but at different levels of intensity.

They all claim to suffer from PFS. Gilles (not his real name), stopped taking Propecia after only three months, having noticed that he had absolutely zero libido. Six years later, his symptoms are unchanged: "The glans on my penis was pale, purple. My penis actually shrank, it felt like someone had torn it off. It was sexual torture."

We met Peter (not his real name) in a Paris café, and he compared his genital pain to that of mutilation. Peter who is thirtyish and lives in the UK, says he felt the first side effects barely 20 minutes after taking his third pill, last May. "I lost 3 kilos in a week. At first I couldn't get out of bed. Now I'm at least able to walk, but I have to pee 15 times a day, and I sleep maybe 2 hours a night."

Alexandre O., 39, who lives in Paris, began taking Propecia in 1999, as soon as it was introduced into the French market. He immediately noticed memory problems, panic attacks and social phobias: "Someone would tell me something, but an hour later I would have forgotten it. My colleagues thought I was doing it on purpose to get fired." He says his perception of reality was altered: "I saw things around me as if they were in a painting. I was a spectator looking at my own life."

A chain of causation between such symptoms and the active ingredient in Propecia has not yet been scientifically established. The medical school at Northwestern University in March 2017 published a study using a sample of 11,909 men who took finasteride. 1.4% of them (167 men) developed persistent problems getting an erection over a median time of 3.5 years after stopping treatment. Another study done by the University of Milan, published in July 2017, focused specifically on PFS. Of 16 patients who were affected after having taken the drug, the researchers pointed out major depressive disorders and major alterations in neuro-active steroids, the hormones linked to the nervous systems. Other studies are currently under way.

A foundation in the USA

For the moment, our only certitude is what the molecule does: finasteride blocks the action of the 5-alpha-reductase enzyme, which transforms testosterone into another hormone, DHT (dihydrotestosterone). DHT is known to cause hair loss. But there is a problem: DHT also significantly affects both the libido and fertility, as well as other biological factors.

When USA-based Dr. John Santmann took our call, he did not mince words. "When you take finasteride, you are eliminating the effects of testosterone," explained this specialist who created the PFS Foundation in New Jersey after his son's suicide. "You don't need to be a ranking scientist to figure out that finasteride is probably not a good idea. You're ruining your body for aesthetic reasons. It's insane!"

In September 2016, the Foundation began offering a support service for victims. Its director, Philip Roberts, a former journalist, has answered more than 1,000 requests for information for information from men arounds the world, including bewildered physicians: "Two of them asked for advice about their own symptoms. One is in South Africa, the other in Delaware."

Despite his efforts, the preventative work of Dr. Santmann dealing with Propecia had not reached Europe until recently.

In France, Gilles saw no warnings. "I asked my pharmacist very clearly: Are you sure there are no problems with Propecia?" He answered, amused, was "Absolutely not."

Like all the victims, Romain Mathieu, who at the time was studying at an important business school in Paris, began harassing doctors in a quest to figure out what was happening to him. He and his mother saw 30 of them in all.

“We spent a lot of time, and we were turned down flat by a number of them,” says Sylviane regretfully. “The practitioners didn’t understand my son’s condition, and sometimes they didn’t believe us. When we’d leave the doctors’ offices, Romain would nearly put his fist through the walls. He couldn’t stand hearing over and over again, ‘At your age, this condition isn’t possible.’”

Four years after he began experiencing side effects, and two years after he stopped taking Propecia, Romain and his mother finally found a doctor who actually helped them: Dr. Gontier, in Mantes-la-Jolie, a GP specializing in functional medicine (which investigates the underlying causes of diseases).

Unlike other specialists, he didn’t look at a single symptom, but at all of them. Dr. Gontier prescribed a series of intensive biological tests for Romain. Three months later, the tests came back: the young man’s intestinal wall and flora – crucial components of the immune system – were seriously damaged.

Romain then saw two gastroenterologists, Jacqueline Warnet and Louis Berthelot. Dr. Berthelot is currently following 12 patients who have taken finasteride: “Their problems are huge, and each patient reacts differently. Here’s an example: I have a patient who can no longer get an erection but when we test his testosterone level it is normal! This is why these men are told they’re crazy. But they’re not. We’re still learning about these symptoms.”

Is it only finasteride that causes these symptoms? we asked Dr. Berthelot. “The molecule is directly implicated. But I also think certain people are more vulnerable than others. I mean, if you strike a match in the middle of a forest, without knowing if the twigs, wood and leaves are damp or dry, sometimes nothing happens. Other times everything bursts into flames. And the flames don’t stop.”

Improvements in some of Dr. Berthelot’s patients have been noted, but there have been no complete remissions.

Most men dealing with PFS are not fortunate enough to be treated. Most of them are on their own, their only recourse is exchanging advice with fellow patients on the Internet. Gilles fasted for 40 days. Alexandre O. took a slew of vitamins and proteins; he tried meditation, sea baths, massages, acupuncture, electrical stimulation. Romain and his mother were up for anything: “For my son, I would have gone to the end of the world. I even sent him to see a shaman in Thailand.”

‘You fight or you fall apart.’

In 2015, Romain found the strength to interview for a job in the mergers and acquisitions department of a major bank. He thought that the overwhelming workload might make time pass faster for him.

“Romain made it!” said Sylviane, so proud. Her son would be working at Deutsche Bank, a prestigious institution. He was also advising his friends who were also looking for work: “It helped him hang on for a time in spite of his illness.”

But Romain soon realized he was physically incapable of working. He would have to miss his first day of work, in early July of 2016. He was just too exhausted. Sylviane says, “In the end, my son was banging his head on the walls from the pain; he was so tired. Not being able to

go to his job at the bank was the last straw. It definitely contributed to his wanting to leave the world.”

Romain could feel his strength ebbing. He quietly began preparing his departure, putting his personal effects into suitcases, his books into cardboard boxes. He mowed half the lawn and remembered to warn his sister that the lawnmower was broken.

“That was the last thing he said. Romain left us the way he lived his life: doing as much as he could for us,” says Marion.

After Romain’s death, Sylviane decided to fight against finasteride, to support victims of the drug. She says she had no choice: “You fight or you fall apart.”

Today she spends her days and nights on Facebook and on the phone, working endless hours without a break. “I often get calls for help from young people in trouble, threatening to take their lives.” They also ask her to explain their condition to their loved ones, who are unaware of what they are going through.

In the summer of 2017, Sylviane met with lawyers from the Dante firm, who are working on lawsuits against Mediator and Dépakine. Charles-Joseph Oudin, Esq. is assembling more than ten victim dossiers, and is looking for others to join his action.

“We’re hoping to file our lawsuit against the laboratory in early 2018, or in the spring. These will be individual suits, which may be joined together.” For the moment, the objective is to establish a causal link between the drug and the pathology in each dossier. “We may then decide to file a criminal case, if the elements of the case are justified, or we may seek only compensatory damages.”

At the same time Sylviane began legal proceedings in September 2017, she and the father of another young victim founded the AVFIN Association to “help victims of finasteride.” AVFIN’s mission is to educate patients and doctors, to obtain validation for the victims and get them the medical help they so desperately need. Sylviane is also in regular contact with the ANSM, alerting its agents to the victims’ situations. She is also trying to introduce a maximum number of cases to the agency’s pharmacovigilance department, which notes the detection of undesirable side effects of medications.

“It’s horrible, but the more suicides there are, the more people will talk about this,” says Sylviane.

At the ANSM, Dr. Caroline Semaille, director of the Dermatology Department agrees. “If the patients don’t tell us about their symptoms, we don’t know about them and cannot do anything about them.”

In April 2017, the European Medicines Agency recommended that all product inserts replace the term “depressed mood” with “depression,” and add “risk of suicidal ideations” to all products containing finasteride. These changes were documented officially in an information bulletin released by the ANSM on October 26.

“No one forces patients to take finasteride,” adds Caroline Semaille. “What is important is that they be able to decide, that they be cognizant of what they may be risking if they take the drug.”

So is it enough just to warn patients about the risk of depression and suicidal ideation? According to our investigation, the symptoms experienced by the victims we met go way beyond these risks. And according to the statistics available from its pharmacovigilance arm,

the ANSM has received 45 French cases of side effects after exposure to finasteride, of which three suffer from severe asthenia (intense fatigue), two from persistent insomnia, one with cognitive difficulties, one with behavior anomalies, and one suicide.

Despite all these unexplained risks, and the purely aesthetic, limited benefit of finasteride, the European Medicines Agency stipulated in April 2017 that the risk/benefit balance of Propecia “remained unchanged,” aka a favorable rating.

The MSD Laboratory, the French subsidiary of Merck & Co., reminded us of this, and in a written response to our questions, they wrote:

“We pay a great deal of attention to the quality and the safe use of our medications. We trust in the rigor of the scientific studies that helped develop Propecia 1 mg.”

While she waits for other studies to be finished, Sylviane has developed her own way of investigating Propecia. She goes to see specialists, pretending that her son is losing his hair and that he is unhappy about it.

“It’s hard pretending,” she sighs. Sometimes the specialist offers her finasteride, claiming that it “has no side effects.” Sylviane listens to him or her patiently, then retorts, “I’m Romain Mathieu’s mother. My son killed himself because of finasteride. And I can give you the names of many others who are at risk of taking their lives or who have already done so.”

Have you taken finasteride and are you suffering side effects from it? It is essential that you notify the pharmacovigilance section of the ANSM. Please let your doctor know, and go to this page on the internet: [Solidarites-sante.gouv.fr](https://solidarites-sante.gouv.fr)

Changes in the product inserts

France: In 2009, ten years after Propecia came on the market, the words “persistent difficulties in getting erections, even after stopping treatment” were added to the insert. In 2010, “risk of male breast cancer” was also added. Two years later, the ANSM published a bulletin saying that “finasteride is under special vigilance in the European market.”

Europe: In April 2017, the European Medicines Agency recommended changes in the inserts for all medications containing finasteride in the 31 countries of the EEC. The manufacturers were ordered to replace “depressive mood” with “depression,” and to add the “risk of suicidal ideation.” The ANSM waited six months to publish, on October 26, a bulletin with these new changes noted.

USA: In April 2012, the FDA required that product inserts mention a number of side effects that persisted even after stopping the medication: problems with libido, erections, ejaculations, orgasms, risks of infertility and/or a decrease in sperm quality, which may disappear or diminish after stopping treatment.

New Zealand: In 2016, this island in the Pacific was the first country to recognize that “post-finasteride syndrome may affect certain men who have taken finasteride,” including physical, mental and neurological side effects, which continue after stopping treatment.

South Korea: The authorities require that depression and suicidal ideation be noted on the product insert.

Class action suits

1300 victims of finasteride have now filed claims against Merck. They accuse the company, in a class-action suit, of not informing them of the risks of the drug’s serious side effects before 2012. This group action allows individuals to collectively sue for recognition of their rights and/or their damages. This option has been available in France since January 2016, if the plaintiffs are joined in an association. 2000 families of the victims of Dépakine (a drug that was prescribed to pregnant women and is accused of causing autism in children) used this legal tool for the first time in December 2016, at the High Court in Paris.

The suit brought against Merck, which was scheduled to begin in the fall of 2016, was pushed back to September 2017, but will now presumably take place in February 2018.

In Canada, two similar class action suits are under way, involving nearly 500 victims.

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**'One Morning, My Penis Stopped Working'
Gilles' Propecia Ordeal**

In March 2010, this man, 25 at the time, was taking Propecia to fight his hair loss. Today he is still suffering the drug's side effects.

By Camélia Echchihab and Emre Sari

Editor's note: This English translation was done by a third party. The original French version can be accessed [here](#).

"One morning, it didn't work. I felt my penis had stopped working. It was brutal."

That was March 2010. For three months, Gilles (not his real name) had been taking Propecia, made by American pharmaceutical company Merck, to slow his hair loss. The young man, 25 at that time, and a student studying chemistry, immediately suspected side effects from taking the drug.

He immediately went to research the drug on the Internet, and in the forums he found hundreds of stories by people who were in the same situation. After taking finasteride, the active ingredient in Propecia, these men spoke of their disappearing sex lives, of not being able to get an erection, of no longer experiencing pleasure in bed.

"I said to myself, 'What the hell have I done?'"

Gilles never took another orange octagonal pill, but it was too late. Now, six years after stopping Propecia, he is still in very bad shape.

"It's mutilation, it feels like they've torn off my penis." The sexual pains are accompanied by mental problems. "This disease steals your personality, along with everything you love. You don't feel love any more. I could perhaps have accepted giving up women, but I am also stuck intellectually."

Gilles has trouble concentrating, memorizing information, especially in the short term. He has trouble even reading, and often spends his days watching videos on the Internet. He cannot work, can barely go outside his home. He is anxious all the time, and lives on welfare from the government.

"In the mornings, I no longer even want to open my eyes."

On his own

Gilles is bitter, often thinking back to when he took that first little pill, and he blames his dermatologist. "He prescribed it without warning me – except for a possible diminution of my libido."

Same thing with the pharmacist. "I remember asking him clearly, 'Are you sure there are no problems with Propecia ?' And he answered, amused, 'Absolutely not.'"

Neither practitioner told him that the molecule affects male hormones. "I would never have taken it had I known. In hindsight, I feel I was caught in a trap."

Finasteride blocks the body's production of DHT, a hormone derived from testosterone, which is responsible for male hair loss. But it also influences sexual activity, fertility and other biological factors.

Gilles is exhausted, dejected, looking back at the 30+ doctors he has seen since. Neurologists, infectious disease specialist, urologists...

"They don't listen, they don't want to investigate beyond the one consultation."

Left to his own devices, he trolls the forums, PropeciaHelp.com and SolvePFS.com, looking for a cure: he has tried fasting, diets, immunotherapy...

"I fought way beyond what was possible," he says. At one time he also joined a victims group to talk about the disease.

At the end of our interview, at a café in Paris, Gilles sees a man who is nearly bald sitting at the counter:

"See?" he says. "Today I could be happy as that guy."

Around the world, hundreds of men are reporting ordeals similar to Gilles'. We spoke to ten of them. After having taken 1-mg doses of finasteride, these men experienced serious sexual, cognitive and physical problems, which continued after the treatment ended.

They claim they are affected by an unrecognized illness, post-finasteride syndrome. In all, nearly 128,000 Frenchmen were exposed to the medicine in 2016. In France, it is included in 23 generic drugs produced by 16 laboratories. In addition to fighting hair loss, it is frequently used to treat enlarged prostate, prescribed in 5-mg doses.

Warnings have been issued by health authorities in several countries. Since June 2017, the product insert mentions risks of "depression" and "suicidal ideation." Some doctors have expressed concerns about the side effects of finasteride. But despite these largely unexplained risks, and benefits that are limited and aesthetic in nature, the European Medicines Agency issued a bulletin in April 2017 saying that the risk/benefit balance of Propecia "remains unchanged," aka a favorable report.

In the USA and Canada, nearly 2000 victims have joined together in lawsuits against Merck & Co., which introduced Propecia to the market in 1997.

In a written response to our questions, MSD, the French subsidiary of Merck & Co., wrote:

"We pay a great deal of attention to the quality and the safe use of our medications. We trust in the rigor of the scientific studies which helped to develop Propecia 1 mg."

In France, victims are beginning to mobilize, and plan to sue in 2018. Their lawyer, Charles-Joseph Oudin, is calling for others to join him. Sylviane Mathieu, whose son committed suicide because of the multiple side effects he experienced – which he claimed were caused by Propecia – has founded an association, AVFIN, whose acronym in French stands for "Aid to the victims of finasteride."