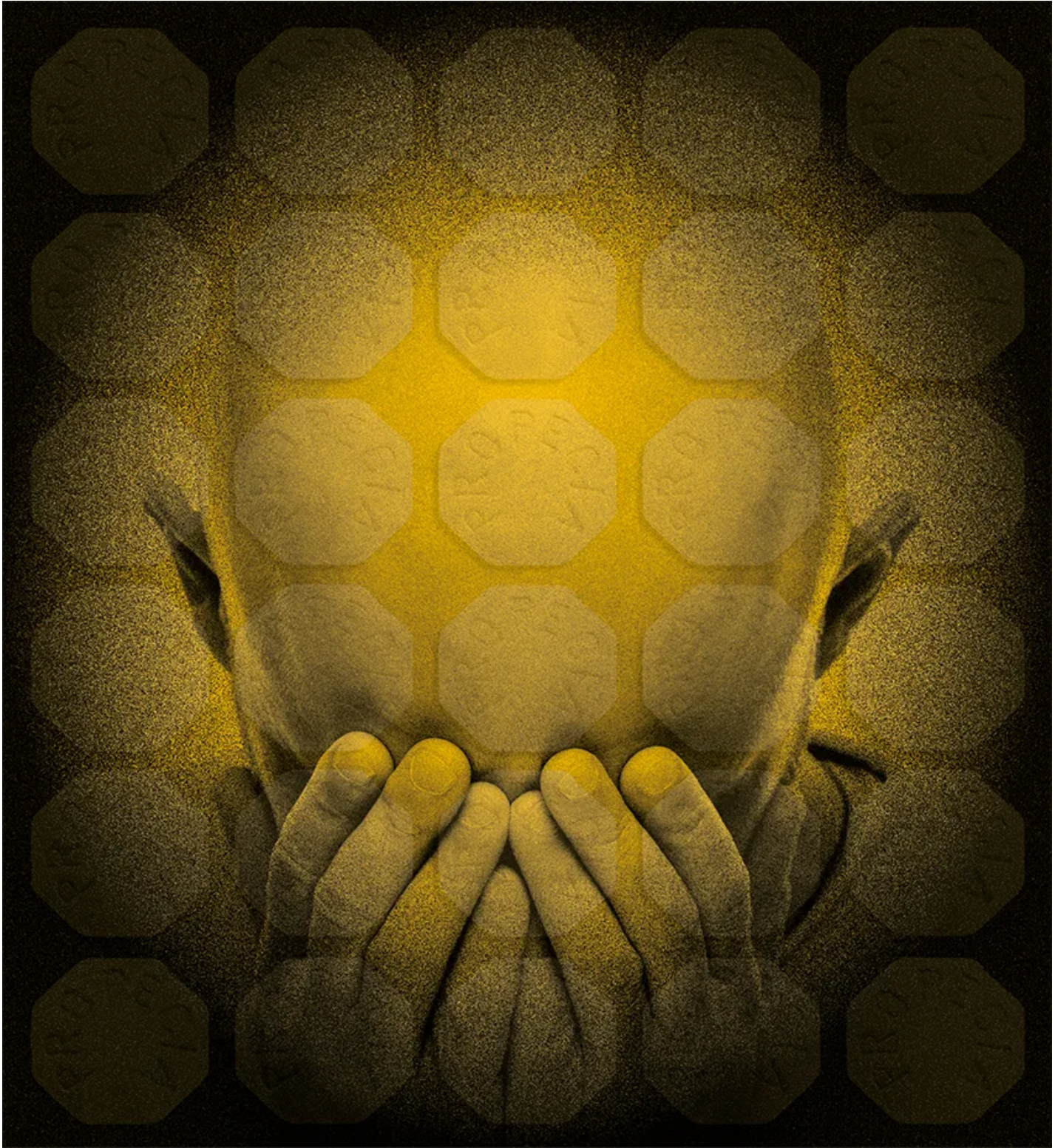


1843

MAGAZINE

Would you risk a breakdown to cure baldness?

Thousands of men claim that finasteride has given them devastating
and long-lasting side-effects



Apr 5th 2024

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By John Phipps

Ben's barber was the first person to notice he was losing his hair. After that it wasn't long until everyone else noticed too. He was a postgraduate student in his 20s, tall and attractive in an equine way. But soon his receding hairline became an obsession. It was the last thing he thought about when he went to bed, and the first thing he thought about in the morning, when he would wake to find dark hairs scattered on his pillow.

Like a growing number of American men, he decided to treat his hair loss. First, he tried minoxidil, an over-the-counter scalp treatment sometimes sold as Rogaine or Regaine. It didn't work. He lost more hair and grew more obsessed.

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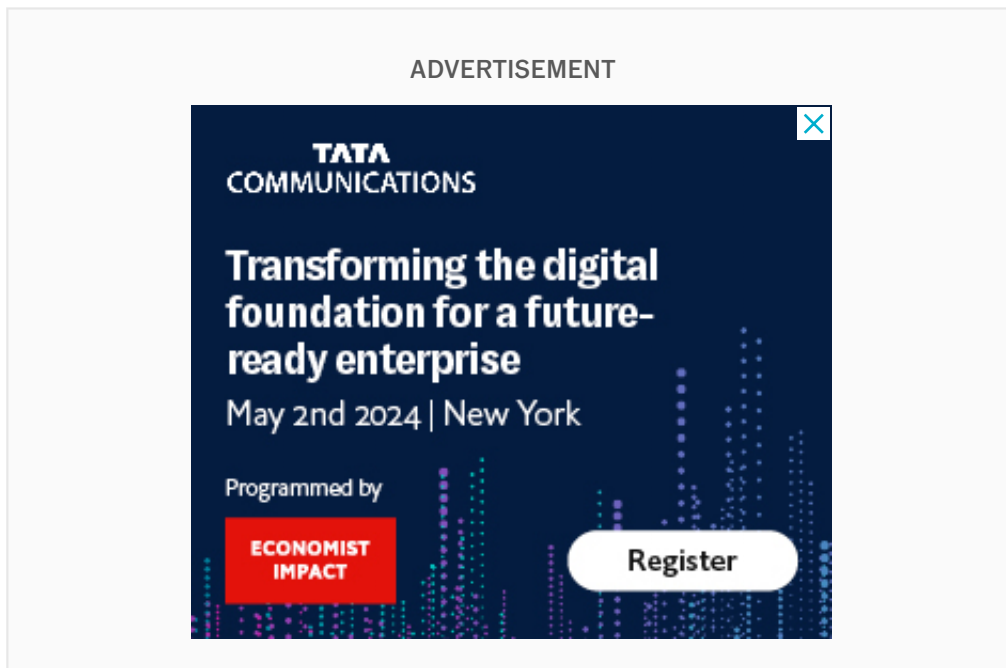
An advertisement for Economist Impact. It features a light blue background with a white border. At the top, the word "ADVERTISEMENT" is centered in a small, grey font. Below this, the main text "Book your early bird pass today and save £400" is displayed in a large, bold, black font. The "£400" is highlighted in a red box. Underneath, "Expires on April 4th 2024" is written in a smaller black font. At the bottom left, there is a red rectangular box containing the text "ECONOMIST IMPACT" in white. At the bottom right, there is a dark blue rounded rectangular button with the word "Register" in white. A small blue "X" icon is located in the top right corner of the advertisement area.

There was another treatment available: a drug called finasteride, which hair-loss specialists generally agree is the most effective treatment for male-pattern baldness. Merck, the pharmaceutical company that developed it, sells it under the brand name Propecia, but ever since its patent expired in 2013, countless generic treatments have become available. Finasteride works by blocking the production of the male sex hormone that causes hair follicle miniaturisation, the process that makes men go bald. Men's health websites peddling finasteride claim that nine out of ten men who use it stop balding, while seven out of ten regrow some of their hair.

But Ben was unwilling to try finasteride. He knew that this hormone-blocker came with a risk of depression and sexual side-effects: it could leave you unable to get erections and change the consistency of your semen. Some men believed these side-effects persisted after they stopped taking it. They referred to this as post-finasteride syndrome (PFS).

Finasteride works by blocking the production of the male sex hormone that causes hair follicle miniaturisation, the process that makes men go bald

Finasteride, which has been used to treat male-pattern baldness since the 1990s, is widely considered to be a safe drug with rare and reversible side-effects. The existence of PFS – when symptoms last at least three months after people stop taking the drug – is disputed among scientists. Although certain studies have suggested that finasteride may be associated with persistent psychological or sexual symptoms, a causal link has not yet been proved. Still, America’s Food and Drug Administration (FDA) was sufficiently concerned that in 2010 it required Merck to add a warning to the drug’s packaging about the risk of depression, and two years later about the risk of persistent sexual dysfunction. In 2022 suicidal thoughts was added to this list.



Ben wanted nothing to do with the drug. Until the

BEN WANTED NOTHING TO DO WITH THE DRUG. Until the pandemic changed his mind. He spent the summer of 2020 pacing between the two mirrors in his small apartment, becoming increasingly anxious and obsessive. He spent hours each day with only his reflection for company, watching his hairline as it peeled back on his head. Eventually he raised the issue with his psychiatrist, who advised him to try finasteride. After a year of hair-related anguish, Ben took the plunge. He began applying a finasteride gel once a day to his scalp and waited for something to happen.

Ben was young to go bald, but not that young. Baldness affects about one in five men in their 20s, one in three in their 30s and more than half in their 40s. While a popular myth holds that it travels through the maternal line, hair loss depends on genes inherited from both parents. Doctors say the best way to guess if you'll go bald is to look at your family history, but the probabilities are still murky. The truth is just that it happens or it doesn't.

Although some research suggests that hair loss can damage professional and romantic prospects, its most destructive effects begin and end in the male psyche. Going bald can make men – especially young men – feel old, unattractive and unhappy. Often, it makes people unhappier than they feel they should be. This disparity – between how much men care about going bald and how much they feel they should care – can

itself become a source of shame.

Ben was unwilling to try the drug. He knew that this hormone-blocker came with a risk of depression and sexual side-effects

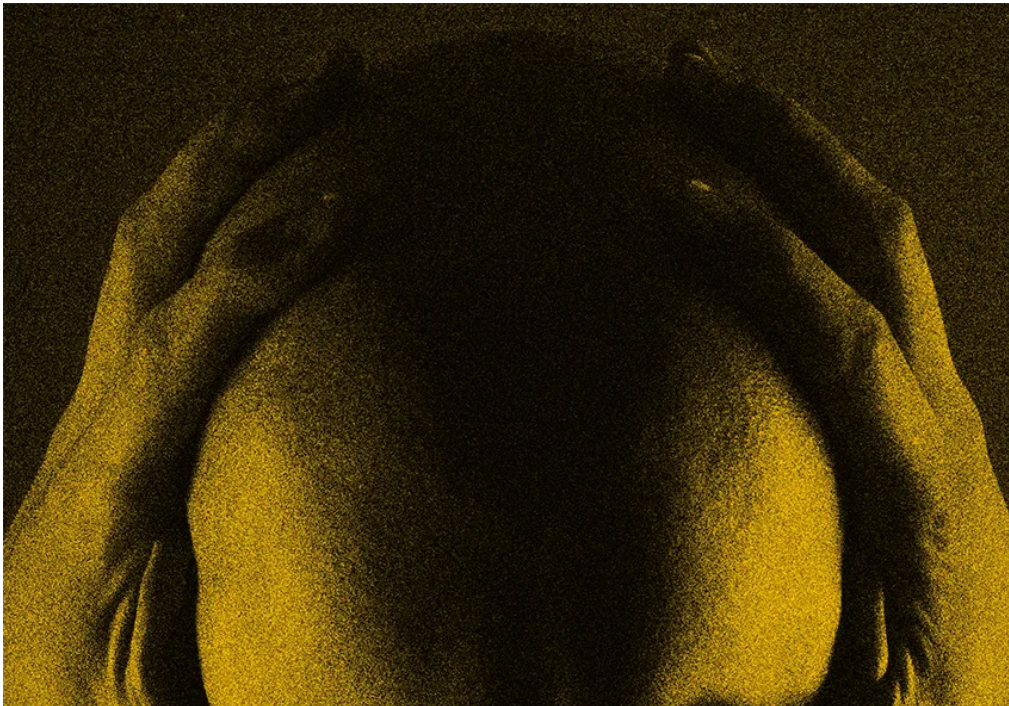
Hair loss is frightening because it can transform a man's appearance. Acquaintances fail to recognise you. Your father's face stares back in the bathroom mirror. And people can be cruel. I remember hearing a female friend dismiss a romantic prospect with two words: "he's bald."

Ben's friends, of whom I am one, reassured him. By that point, in spring 2021, he'd been using finasteride for two months. He hadn't stopped balding, but he knew it could take up to six months for the drug to have any effect. He began to wonder if his hair really did matter all that much. "I love *you*," his girlfriend told him one evening, "not your hair." That night he threw away his remaining prescription.

It was a few days later, when Ben was at a shopping centre, that the shitstorm started. As he queued for lunch, his heart started pounding. His surroundings fractured. The light and noise of the food court were suddenly unbearable, as if the world around him was screaming. It felt as though some inhuman entity bent

on harming him was trying to force its way in at every nerve ending. He staggered home, texting his psychiatrist, who told him to go to the emergency room if he was really worried. He decided to wait it out. After a few hours, the feeling passed.

Ben guessed it was some kind of panic attack, but it was more acute and intense than any he'd experienced before. While researching finasteride, he had read of men who claimed they suffered from irreversible side-effects, including impotence, anxiety, insomnia and depression. Some said these symptoms never disappeared. Ben didn't think it could happen to him, but now he was worried. Days later he had another attack. Then another. Other things started going wrong with his body: he was shedding weight and his muscles were losing definition.





Returning to the online forums, he read about men whose experience mirrored his own: a sudden onset of terrible symptoms that started in the weeks *after* they stopped taking finasteride. They called it “the crash”.

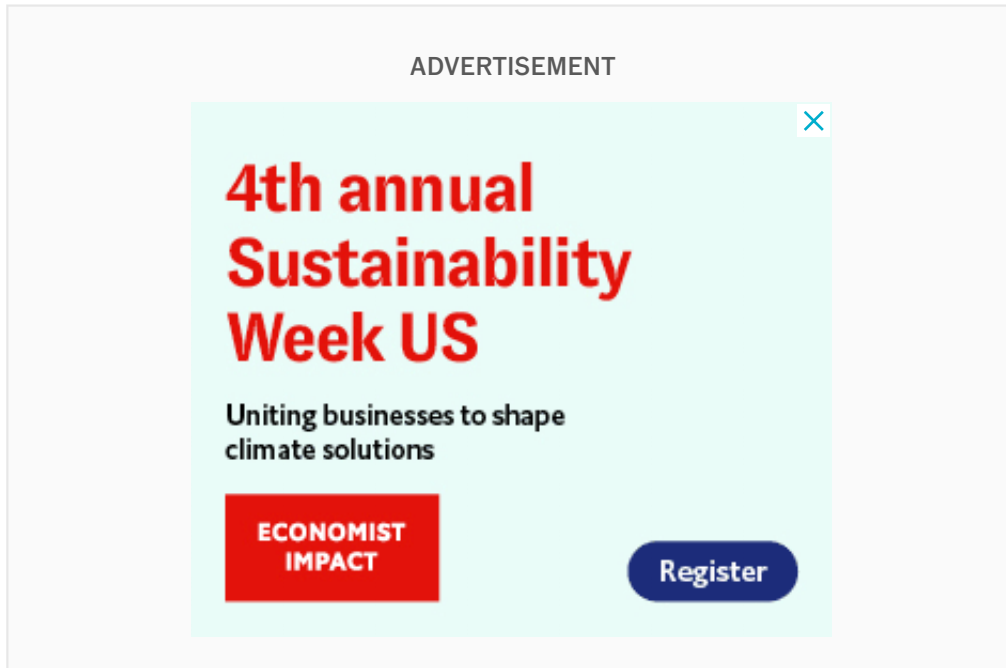
“I’m really freaked out over these meds,” said Ben in a message to a friend.

“You’ve stopped taking everything though, right?” his friend replied.

Ben texted back: “What have I done?”

In 1974 Julianne Imperato-McGinley, an endocrinologist at Cornell Medical College, travelled to a remote village in the Dominican Republic where some girls were said to turn into men. She discovered that these girls were actually biologically male, but lacked the enzyme that transforms testosterone into dihydrotestosterone (DHT), which stimulates the development of sexual

characteristics. Without DHT, the babies were born with genitalia that looked female, and they were raised as girls.



When they hit puberty, however, they produced enough testosterone that their bodies started to transform. Their voices dropped, they grew a scrotum into which testicles descended, and what had looked like a large clitoris turned into a penis. They were known locally as “Guevedoces”, which means “penis at 12”.

The enzyme the Guevedoces lacked was called 5-alpha-reductase (5 α R). Since Imperato-McGinley shared her findings, populations with 5 α R deficiencies have been discovered in many other places. Today these groups are studied extensively by scientists and sociologists.

Imperato-McGinley’s paper also made a splash outside

academia. Researchers at the drug company Merck were particularly interested in its findings about adult Guevedoces. The men had patchy facial hair, no acne and their prostates didn't get bigger with age. They also didn't experience male-pattern baldness.

Hair loss is frightening because it totally transforms a man's appearance. Acquaintances fail to recognise you. Your father's face stares back at you in the bathroom mirror

Merck reckoned that if it could develop a drug that replicated the effects of the Guevedoces' natural enzyme deficiency, they could treat benign prostate enlargement, a common condition in older men that can affect urination. Proscar, the company's prostate-shrinking drug, was approved by the FDA in 1992. It contained 5mg of finasteride, an ingredient which blocked the production of DHT by inhibiting the 5 α R enzyme (studies show that just 0.2mg of finasteride causes a 60% decline in DHT levels).

Proscar was released to huge fanfare – some analysts predicted it would soon be making the company \$1bn a year. Unfortunately for Merck, Proscar didn't prove as lucrative as it had hoped (its sales in 1996 were a mere

...ative as it had hoped (its sales in 1998 were a more modest \$141m, equivalent to about \$280m in today's money). But its researchers knew there was another exciting finding in Imperato-McGinley's paper. In 1997 the FDA approved Merck's new drug, Propecia, a pill containing 1mg of finasteride, as a treatment for male-pattern baldness. It seemed as though something men had been clamouring for since the dawn of modern medicine had finally arrived.

After those first attacks, Ben's symptoms came on fast. His muscles began wasting away. He stopped getting morning erections, then erections at any time of the day or night. His sex drive withered. When he lay in bed beside his girlfriend he felt nothing. A calcified plaque began to form on the underside of his penis. He became worried that his anogenital distance (the distance between the testicles and the anus, which is associated with sperm count) was getting smaller. He was still losing weight.

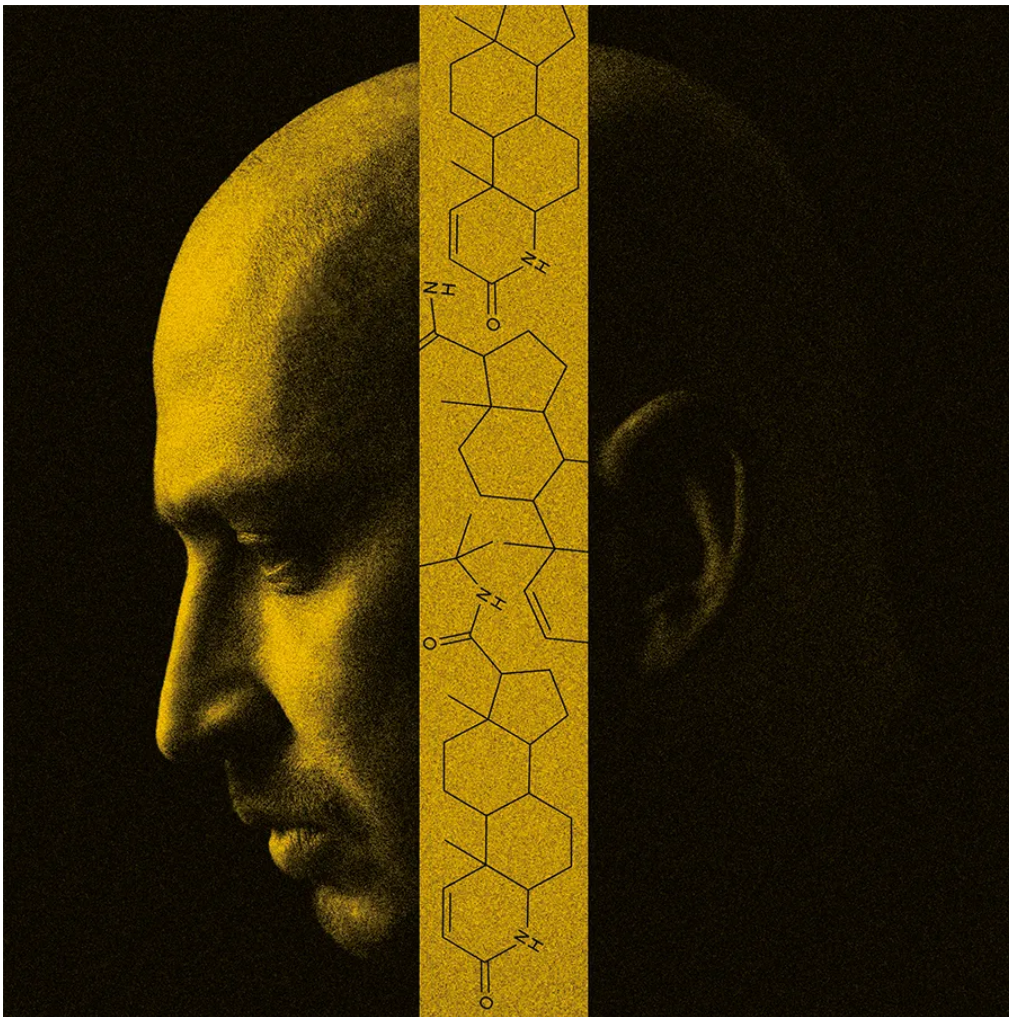
Ben's symptoms came on fast, from every direction. His muscles began wasting away. He stopped getting erections and his sex drive withered away

By June 2021 Ben was having four or five panic attacks a

day. He was 40lbs below his normal weight. Using a cocktail of sedatives, he could manage three hours of sleep a night. Otherwise, he lay awake taking deep breaths, eating calorie-laden nuts and bracing against the next onslaught of terror. He would wake into an all-consuming brain fog. It became impossible for him to read or concentrate. The terror became relentless. He began thinking about ways to kill himself. Ben went to church, the first time since childhood, and prayed for forgiveness.

On the forums some people said this experience never ended; others said their “crash” bottomed out after a year or two, after which they made a partial recovery. One endocrinologist who had published on the subject simply said that there was no cure. The lucky ones, Ben noticed, had been diagnosed with irregular hormone levels and treated accordingly. Men whose hormone tests came back normal, however, were told there was nothing wrong with them, that they needed to get a grip.

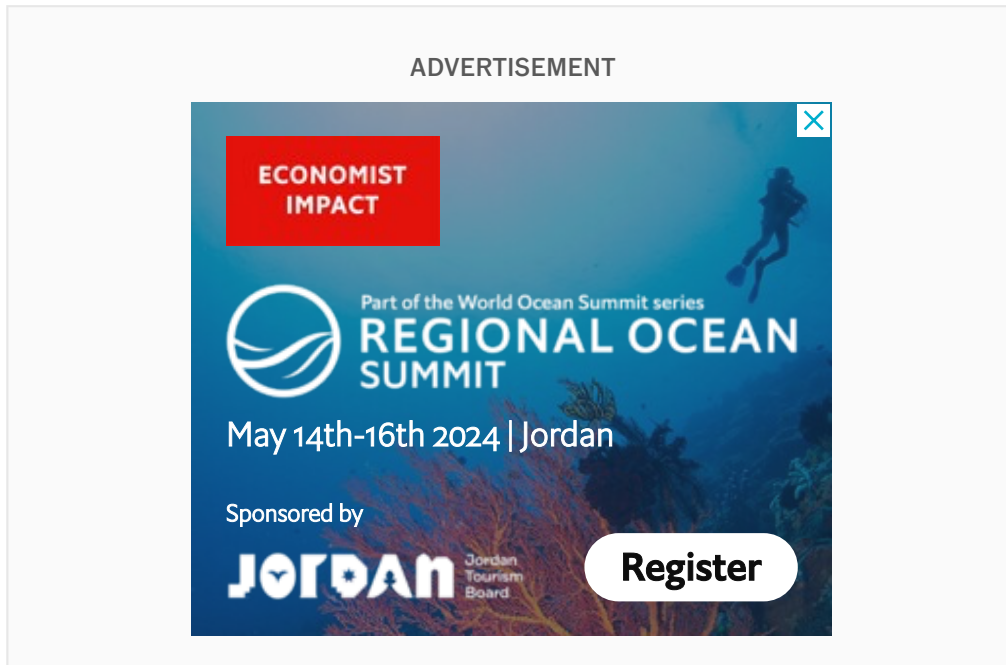
In his doctor’s office Ben broke down, weeping and pleading for help. He persuaded his doctor to send off a blood sample to a lab, praying for the worst results possible. Normal testosterone levels for a young man can be anywhere between 300 and 800 nanograms per decilitre. When Ben’s results came back, his were at 210, low enough to warrant medical intervention. He was referred to a hormone specialist.



Ben was expecting to have to argue his case, so was both surprised and encouraged when the doctor agreed with him that finasteride was responsible for some of Ben's sexual symptoms. But any hopes for a speedy resolution were soon dashed. The doctor refused to prescribe him any hormones unless Ben's testosterone level dropped even lower.

He was devastated. It was as though he'd had a lifeline thrown to him and then snatched away. He felt untreatable, that there was nothing that could be done

to end his suffering. After he left the doctor's office he drove to the top of a multi-storey car park, got out of his car and walked towards the edge.



It's sometimes said that a drug with no side-effects is a drug with no effects. The question is what kind of risk is acceptable. In Merck's trials of finasteride 1mg, it found that about 3.8% of patients experienced sexual side-effects (including difficulty getting erections or ejaculating), compared with 2.1% of the placebo group. They also found that these issues were resolved when patients stopped the drug. Merck has consistently denied that finasteride can cause permanent sexual or psychological side-effects.

As early as 2009, however, Merck knew of 200 reports of depression, including suicidal thoughts. Since then the

FDA has received 843 further spontaneous reports of suicidal ideation, and 200 reports of suicide. At every stage, Merck has decided that there aren't sufficient data to establish a causal link between their drug and these drastic events. In Britain, European Union countries and elsewhere, regulators have required Merck to list depression and suicidal ideation on the label. A spokesperson for Organon (a spin-off company that now owns Propecia) told *1843 magazine* that finasteride is safe and effective and has been approved by regulatory agencies around the world. The spokesperson added that patients with concerns should speak to a health-care professional.

During Merck's extension trials, conducted after the drug had gone to market, there was one patient whose erectile dysfunction persisted more than six months after he stopped taking medication. Merck never followed up with him.

By 2016 around 1,400 Americans had filed lawsuits against Merck, alleging that the drug had caused them to suffer from persistent sexual side-effects. In a court deposition a Merck employee admitted that the company's "adverse events database", which collected reports from health professionals, had no way to record the "persistence" of sexual side-effects, although there were hundreds of reports of patients who had "not recovered" after they stopped taking the drug. In 2018 most of the lawsuits were settled out of court for a combined sum of \$1.5 million.

COMBINED SUM OF ₱4.3m.

He saw himself as facing down an unbearable series of trade-offs. Get your mind back but grow a pair of breasts. Keep your sex drive but lose your fertility. Keep your hair but lose your life

It's hard to know how many men are suffering from PFS. The specialist forum PropeciaHelp has over 7,000 registered users, and the World Health Organisation's adverse-effects drug monitoring database counts almost 20,000 reports for finasteride. Not all these reports will be accurate, but then again most people who get side-effects from any drug don't alert the authorities.

Still, these are small numbers compared with the roughly 2.5m men who were being treated with finasteride in America in 2021. Several hair doctors told me they'd prescribed finasteride thousands of times without ever hearing a complaint (though if you were having a psychological or hormonal melt-down, a hair-loss doctor might not be your first call). Scientists who are unconvinced about PFS bring up the "nocebo effect" – the idea that anxious men could be imagining side-effects based on the negative reports they have

heard.

Yet many men are convinced that the drug is responsible for their ailments. Researching this article I interviewed 13 people who claimed to have experienced persistent and debilitating side-effects from finasteride. All of them were traumatised by their experiences. None would let me use their full name; some said they hadn't even told their families. They'd been sick for years.

Ben didn't jump. Instead, he went home and told a family member – a doctor who had previously dismissed his symptoms as anxiety – about his disfigured penis. The relative said it looked like Peyronie's disease: a condition where scar tissue causes the penis to bend, which mostly affects men over 50. "They were like, wait: we have a 25-year-old with fucking Peyronie's disease," said Ben. "That's when they really freaked out."

Friends and family started pulling strings. Soon, Ben was in contact with multiple specialists. His endocrinologist called with the results of his latest blood tests: his hormone levels had continued to fall. His levels of luteinising hormone, which is produced in the pituitary gland and stimulates the cells in the testes that produce testosterone, were almost non-existent. The endocrinologist prescribed him testosterone replacement therapy (TRT), a gel that he had to apply to his skin once a day.

HIS SKIN ONCE a day.



Another doctor recommended that he replace the TRT with another drug called clomiphene, or clomid, which can stimulate the body's own production of testosterone and has milder side-effects. She told him the pills would make him feel better in six months. Ben couldn't wait that long. He said he was going to carry on taking TRT. The doctor looked worried: taking testosterone supplements, she explained, suppresses two of the hormones that produce sperm. There was a fair chance that TRT would make him infertile. She gave him the number for a sperm bank.

Then a family friend – a gung-ho urologist – told Ben to tear that plan up too. It could take a while for the clomid to work, and Ben's depression was so severe that there was no time to lose. The way to treat his symptoms, said the urologist, was with a hormone

produced by the placenta during pregnancy called human chorionic gonadotropin (hCG). The idea was that this would stimulate the cells that produce testosterone. If, after that, Ben was still having problems with his sexual function, then the urologist said he could give him a penile implant to help him maintain erections. When he got home, Ben googled side-effects of hCG and saw that it caused some men to grow breasts.

This rarely happened, but Ben saw himself facing down an unbearable series of trade-offs. Get your mind back but grow a pair of breasts. Keep your sex drive but lose your fertility. Keep your hair but lose your life. What if he ended up bald with breasts and a limp dick?

By that point, in summer 2021, Ben was experiencing nightmarish pain and confusion. The scalding, white waves of terror came for hours at a time each day.

When they drew back he felt numb and in a dissociative state. Ben thought his mental capacity was diminishing. He often forgot what he was saying or where he had been a few minutes ago. He got lost near his own home. It was as though his brain was a light with someone holding the switch in the halfway position, causing the bulb to flicker. Later, he described the experience as “body horror”: “It felt like deprivation. Thirsty, starving, suffocating, withered. Those were the words I would feel in my head.”

Doctors' search for Americans

By 2016 around 1,400 Americans had filed lawsuits against Merck, alleging that the drug had caused them to suffer from persistent sexual side-effects

Ben had learnt, in the most brutal way, that when you play with hormones there are consequences. He had been scared of becoming a lonely and miserable bald man, but now he was lonelier and more miserable than he had thought possible. Every road back to happiness – or even normality – seemed to travel through more anguish. Sometimes all he could do was lie on the floor and breathe deeply. The suicidal thoughts intensified.

He decided to take clomid after all. The effects of the drug were immediate and unsettling. His muscles felt plumper. He began to experience angry, manic mood swings. There were more doctors' appointments, more conflicting information. "I am unbelievably fucked up," he texted me. "My whole body is imploding. I can't handle this."

On the advice of one doctor, he switched to hCG. After the first injection, he felt no different. This was bad news. He was on the best treatment available, but he wasn't responding. He didn't sleep that night. His brain fog was unbearable, his fear wouldn't lift. This was hell, he thought to himself. He texted friends to say that he

thought he had come to the end. He said the signs were all trending downwards.

Scientists who are unconvinced about post-finasteride syndrome suggest that anxious men could be imagining side-effects based on the negative reports they have heard

The next day Ben jammed the needle into his stomach again. He paced the room and writhed on the floor as he did his breathing exercises. That evening something felt different. He felt able, for the first time in a while, to look at his situation as if from the outside, to see how absurd his life had become. He slept a little better that night. When he woke up, he allowed himself to think: one day this might be over.

Sitting on my desk are two packets of finasteride tablets. I am not losing my hair and have not seen a doctor in months. I do, however, have access to the internet. In recent years, a slew of startups have emerged that claim they will relieve men's embarrassment around going bald. Hims, an American website that prescribes treatments for baldness, skin care and erectile dysfunction, was founded in 2017.

When I first tried to order finasteride from Hims in 2021, the website asked me if I had any relevant medical issues. I invented a history of suicidal thoughts and erectile dysfunction. A doctor contacted me to say that, in light of this medical history, he was not able to prescribe me the drug.

On Freshman, a British website, I added finasteride to my basket and, when prompted before checkout, ticked the boxes for suicidal thoughts and erectile dysfunction. A notice popped up: unfortunately I wasn't eligible for the drug. I unchecked the symptoms. The notice disappeared and I was able to order a prescription. A week later Freshman emailed me to say the site had been acquired by the company that owned Hims. Though it had deemed me unfit for treatment, Hims would now be dispensing my finasteride prescription every month.

Raf, a 46-year-old man who was retraining to be an accountant and lived in a provincial town in England, found out about finasteride on YouTube. He wanted to regrow his hair by the time of his brother's wedding, which was six months away. Raf watched videos where

doctors spoke confidently about its effectiveness. He got a prescription online from Superdrug, a British pharmacy. (I was easily able to order finasteride from Superdrug, despite my invented medical history.)



Within a few months of taking the drug, Raf's testicles started to hurt. He stopped taking it, as the label advised. Soon, he was hit by a wave of inexplicable fatigue. Walking through town he felt disconnected from reality – as though he'd stepped into a dream. He woke up the next morning in despair. His ears were ringing. The world around him moved with an underwater slowness. When he picked up a textbook, he couldn't read the words on the page. For months, he thought about suicide constantly. On his way to work, he was scared to stand close to the edge of the railway

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He remembers hugging his partner and begging him:

“Please, help me die.” When the horror lifted, he was impotent. His partner left him. Today, his life is dominated by brain fog and physical pain. He said he’d lost all pleasure in listening to music. He doesn’t socialise if he can help it.

Raf told me he’d never experienced mental illness or sexual dysfunction before taking finasteride, but added that if he had, he wouldn’t have shared that information with an online retailer. He wanted to keep his hair too badly.

No one knows why some men experience such an extreme reaction to finasteride. Derek Munro, a Canadian bodybuilder and social-media influencer is the co-founder of Marek Health, a website that sells consultations and DIY blood tests to people considering some form of hormone therapy. Munro claims without evidence that PFS is caused by a “hormonal imbalance”. In videos and blog posts, Munro advises men who are thinking of taking finasteride (or those who believe they are suffering from PFS) to buy “hair panels” from his website, blood testing kits that promise a “comprehensive look into the root cause of your hair loss” by analysing hormone levels.

I asked Abdulmaged Traish, emeritus professor of urology at Boston University, whether there was a way of telling which men would get persistent side-effects from finasteride. “If I knew that,” he said, “I would be a millionaire” Rachel Rubin, a urologist who has treated

immortal. Rachel Rubin, a biologist who has treated hundreds of men who claim to have PFS, was equally sceptical: “There’s no data like, ‘the guys who got symptoms had x , and the ones who didn’t had y ,” she said. None of the medical specialists I spoke to could tell me the probable prevalence of persistent side-effects, or demonstrate the mechanism by which the drug was causing people to become permanently ill. They didn’t seem hopeful about getting funding to research these problems. They just kept seeing more patients.

When Ben was a child, his mother would sit on the bed with him after his bath and brush his hair. She would tell him how handsome he was, swooshing his hair this way and that. Ben, who had a difficult relationship with his mother, said these were the only unambiguous moments of affection he can remember.

Ben thinks that he wasn’t really treating the baldness, he was treating something else: unhappy memories, self-hatred

I asked Ben what had scared him most about going bald. “I guess it was like a sense of not being...special? A sense that I had lost something that redeemed me. I didn’t have a sense that I was like a good person

didn't have a sense that I was, like, a good person, before all this happened...The only thing I had of value was physical attractiveness.”

Now Ben likes the way he looks. He doesn't have his hair, but he's got everything else he thought he would lose: his potency, his sanity, his strength (although he still has to inject a low dose of hCG three times a week). He's still with his girlfriend. He thinks that he wasn't really treating the baldness, he was treating something else: unhappy memories, self-hatred. He sometimes spoke to me about the day he threw out his finasteride prescription, just before he fell ill. That night, he said to his girlfriend in bed, “I've realised I don't need to be perfect. I'm good.”

Traumatised by their long illnesses, many of the PFS sufferers I met had found no resolution to their feelings of inadequacy. Some of the men I spoke to still had long hair that they maintained with other hair-loss treatments. Some wore hats or hoods. Others, whose baldness had been stopped by finasteride, were longing to lose their hair. They thought it would signal that their endocrine systems had begun to function again.

With hormonal treatment, Ben's cognition came back in fits and starts. There were days when the brain fog was too thick to see through. Some days he seemed to have no body odour. Some days his libido was shot. His mood went up and down. He began to keep a diary so he could track the effects of any changes to his

medications.

For months, he was obsessively worried about some form of relapse into his old symptoms. Then he began to sleep without trouble. The brain fog lifted and he could read for pleasure again. His libido came back and stayed. He looks a little older than he did, but he's still a very young man. "The big bad thing I was afraid of all my life actually happened to me," he wrote to me six months after he'd started recovering. "So now my anxiety has done its job and can retire."

A while back, and not for the first time, a male friend who knew I was researching the drug cornered me in a bar to ask about finasteride. I told him what I knew: that the drug is the most effective treatment for hair loss. That the overwhelming majority of men can take it without problems but that a small number of people report catastrophic side-effects, which can be permanent. I explained that treatment was almost impossible to find. I said that some men had killed themselves. As our drinks arrived, I asked him whether he would ever take the drug. He told me he'd think about it, if he ever started losing his hair. ●

John Phipps is a contributing writer for *1843 magazine*

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