

I. Intro scene — Friday afternoon at the Emory sleep clinic.

Camille Hartung and her husband, Darryl, are sitting in David Rye's sleep clinic in Atlanta. They've come 600 miles to see the doctor, a sleep specialist, in this shabby room in a shabby building. Over the past two years, Camille, 40, has inexplicably lost her life to sleep. Gets up every day in agony, takes her kids to school, then comes home and sleeps until she has to go pick them up. She manages to stay awake, barely, until dinner, then off to bed again. She and Darryl rarely have sex anymore—she can't stay awake for it. She's gained 20 pounds. She's been called lazy and crazy and depressed. She's been to doctors all over the country and tried every stimulant there is, one of which made her horribly aggressive. She's desperate.

She came here because she wants the drug that everyone in her hypersomnia Facebook group has been buzzing about: flumazenil. Rye's team made headlines in 2012 when he showed that it woke up a hypersomnia patient named Anna. Camille, like hundreds of others, wrote Rye a letter begging him to see her. The day she got the call from his secretary, she burst into tears.

In the office, Rye tells Camille what she's been praying to hear: she's eligible to take the drug. So she takes it then and there, while Rye and his assistant observe and take notes. She places the two little pink pills under her tongue and lets them dissolve for a few minutes. Over the next 10 minutes, she gets hyper and her voice gets louder. The doctors can't tell if it's the drug or just the excitement of finally getting here. Now she has to wait and see. Even if it doesn't work, she's relieved to finally have someone recognize her sleepiness as a real problem.

II. Nut

Six years ago, this was a typical sleep clinic, with Rye seeing apnea and yadda yadda. Then they met Anna, a woman who couldn't stop sleeping. Their research on Anna led to a drug that cured her illness and to a discovery that shocked the sleep/neuroscience field. But that was only the beginning. After their research became public, they started hearing from other Annas... many, many other Annas.

These “sleepyheads,” as they like to call themselves, have two things in common: an incessant craving for sleep, and a yearning for recognition from the medical community.

After years of being spurned by doctors and family members alike, they're forming online communities to discuss symptoms, drug regimes, and personal problems. Thanks to a messy conflict between the Emory clinic, government regulators, and private drug makers, some of these patients, like Camille, are now able to try the magical drug, flumazenil. But while the drug was the catalyst for forming this community, it's only the beginning of what they hope to accomplish: a revolution in the way doctors, scientists, and the public think about sleep. **[or something like that... I think one of the underlying themes of this story, and hopefully what will make it resonate with a lot of people, is going to be about how sleep is such a fundamental part of our health, and yet woefully overlooked by the medical establishment.]**

III. Hypersomnia history/diagnostic woes

[Purpose of section is to explain why hypersomnia is so often misdiagnosed/not diagnosed.]

Begin with what a huge problem sleep is, for so many people, and yet mostly ignored by modern medicine. Sleep is a factor in every chronic disease there is...and yet cardiologists, oncologists, family doctors etc etc don't place much emphasis on it.

Even when you go to a sleep clinic, it's usually run by pulmonologists, who are concerned with sleep apnea --

respiration and airways – not the brain.

Hypersomnia is not a new disease. Literary references to hypersomnia (Dickens' first novel); the first real research on it in the 70s; how it got lumped with narcolepsy. Why narcolepsy is so different.

Add to that problem... hypersomnia often misdiagnosed/conflated with depression. Tell **Jonas's** story. He's 20, from France. Was dismissed by his parents as lazy college kid, even after he had to quit school. Was completely dismissed by his doctors, told he had depression. But then, he actually did get depressed. Hard to sort out chicken and egg.

IV. Anna's story

No one could have ever called **Anna Sumner** lazy. Incredibly accomplished woman. And yet...sleepy. Years of struggle and misdiagnoses...got to a point where her muscles were literally wasting away.

Then she found the Rye clinic, how they found flumazenil. Explanation of GABA... Kathy Parker's story of waking up in the middle of the night, writing GABA on a piece of paper and circling it. Leading them to try the only thing they had left: flumazenil.

Gave her a spinal tap, had to create a new GABA assay for her CSF... she was off the charts. Was as if she were under surgical anesthesia.

The first time she took it, she woke up and immediately said, "I feel alive."

V. Drug supply

The success was bittersweet: She had this miracle cure, but no way to take it outside of the hospital. How she got her supply of the drug from Roche. Sent it over from Basel in a Ziploc bag. She was set for at least five years. After that, she wasn't sure.

The researchers' work on Anna turned into their big study, published in November 2012 in Science Translational Medicine. This was incredibly hard to publish. Why? Because it went up against dogma of the field.

Emory clinic starts prescribing antibiotic which has same effects on GABA...seems to work for awhile but then stops. They publish open-label trial, in the process of doing placebo controlled.

End section with Emory clinic suddenly fielding a crazy number of inquiries from hypersomnia patients. Not really knowing what to do with them all.

[Interlude: If I can get them, photos of some of the application packets/letters that the Rye clinic has received from desperate patients...could make for a cool slideshow or short interlude. Camille mentioned that she wrote HELP on her letter in giant letters. I interviewed the young woman in the clinic who spends a lot of her time going through all of this correspondence. Shows just how overwhelmed the clinic is.]

VI. Lloyd

On the other side of the world, **Lloyd Johnson** read Rye's paper, too. His backstory – ran a successful small business, would go around the world giving workshops on hypnotherapy. Then he got sleepy.

Went through all kinds of herbal remedies, yoga, alternative medicine. Then found Rye's paper....

Around this time Lloyd, a natural leader, started the YouTube channel and the Facebook group.

In the Facebook group, everyone started talking about Rye's big paper... all of these patients were amazed to hear that other people had the same symptoms they did: limbs feeling heavy. Agony to wake up. Like being sedated all the time. They also shared personal struggles.... [**Perhaps I'll actually quote from the Facebook group postings from that time? I'm part of the group but will need to get the appropriate permissions.**] **some** were estranged from their parents, **others** actually divorced because of their sleepiness. Show their desperation and their excitement over finding this community.

Lloyd, despite this new social network, was getting more and more despondent. Told his mother he wanted to kill himself. She convinced him to wait until after Christmas.

By that point, he was determined to try flumazenil for himself. found a local doctor who happened to have been using flumazenil to treat drug addicts. He convinces the guy to give it to him for his sleepiness. It wakes him up, just like it did for Anna.

Lloyd made videos showing how the drug worked for him (he uses a pump in his stomach) and they soon were being watched by everyone in his hypersomnia networks.

[can embed that first video of Lloyd getting the drug]

Soon Rye's patents started asking him about this guy in Australia who could get flumazenil.

Rye is livid — we should be able to do this here, land of the free.

[Alarm clock interlude here (if there's enough good material)...photos/stories of what people do to wake up. Vibrating alarms, winches, crazy noises...]

VII. Rye versus the FDA

Story of Rye figuring out how to get the drug cheaply, confronting the FDA, having argument about it at clinic with Trotti. He starts prescribing it to patients in spring 2013. Local compounding pharmacy selling it for about \$1/pill.

End section with FDA finally telling Trotti that it's OK for them to do this. Murky regulatory waters, no one knows how to navigate them.

By December, Rye and Trotti had prescribed it to about 75 people with hypersomnia. More than half reacted well to the drug.

Problem is, they have no money. They want to figure out what the sleepy chemical is, they want to do full-scale clinical trials. They just don't have the resources. Meanwhile, hundreds on the waiting list.

VIII. First patient conference, they're finally meeting each other

That's what led to the conference in March in Atlanta...Lloyd organized it, then came over and stayed in Rye's house for three weeks. Expected a few dozen people to come and turned out to be 155.

Lots of stories from conference of how grateful they were to meet each other, to finally be taken seriously by doctors. There was **Jackie**, a 50-year-old from Pittsburgh, who was given a narcolepsy drug that made her fall off her bed. And **Pam**, from Minnesota, whose mother and brother think she's a hypochondriac. And **Lauren**, a 30-year-old from Maryland, who sometimes goes out to sleep in her car during work, and one time took a nap across chairs

of her office conference room. Jonas came all the way from France, and Camille from Florida. Anna was there, and so were her parents. There were spouses and siblings, too, who commiserated with each other about what it's like to live with a sleepyhead.

Story of Rye, huge guy, crying in front of the group? [**too much?**] Making a plea for more money.

Conference raised \$5,000 through t-shirt sales and the like. Not nearly enough, but it's seeding this official foundation now for fundraising purposes. Hoping to have a rich person come out of the woodwork to fund the studies. Wouldnt' cost that much money in the scheme of things...

Circle back to Camille, who was at the conference...what it meant to her?

Coda, maybe, of how Camille is now doing on flumazenil? Was it the lifesaver for her that it was for Anna and Lloyd?