

CHAPTER 4:



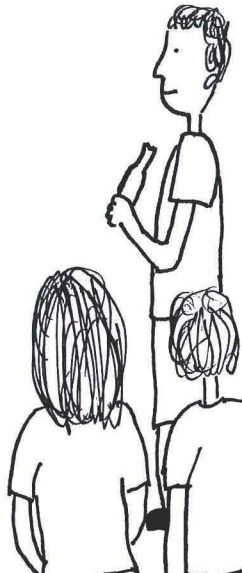
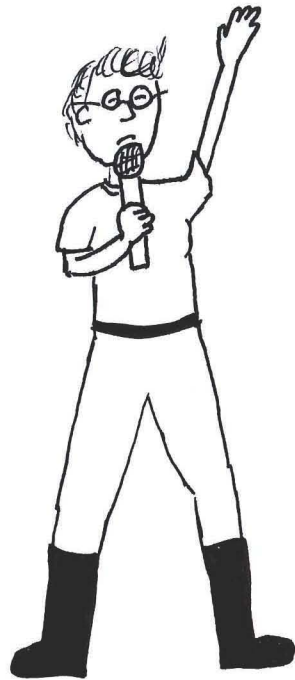
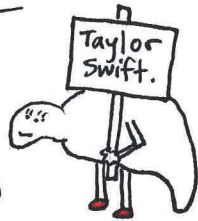
Wait.

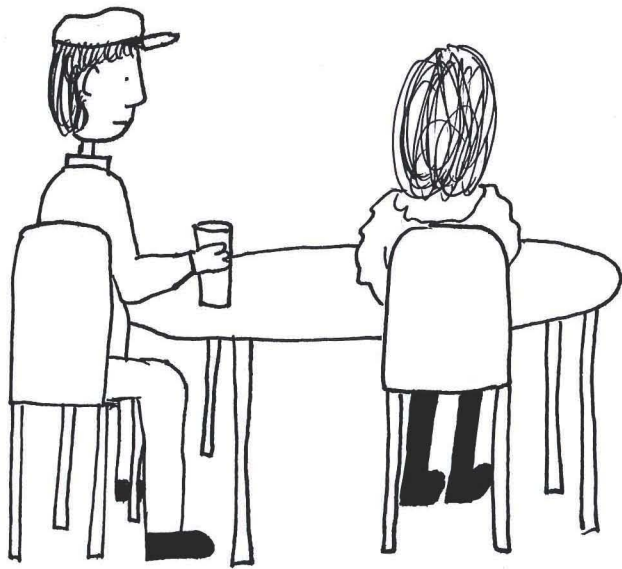
My friends and I are regular karaoke-goers. My specialty is over-acted, over-sung, extra-interpretive-dance-moves semi-country-pop.

We go to spend time with each other, to laugh at ourselves, to celebrate and cheer those among us who are actually great singers.

We go for the karaoke scene.

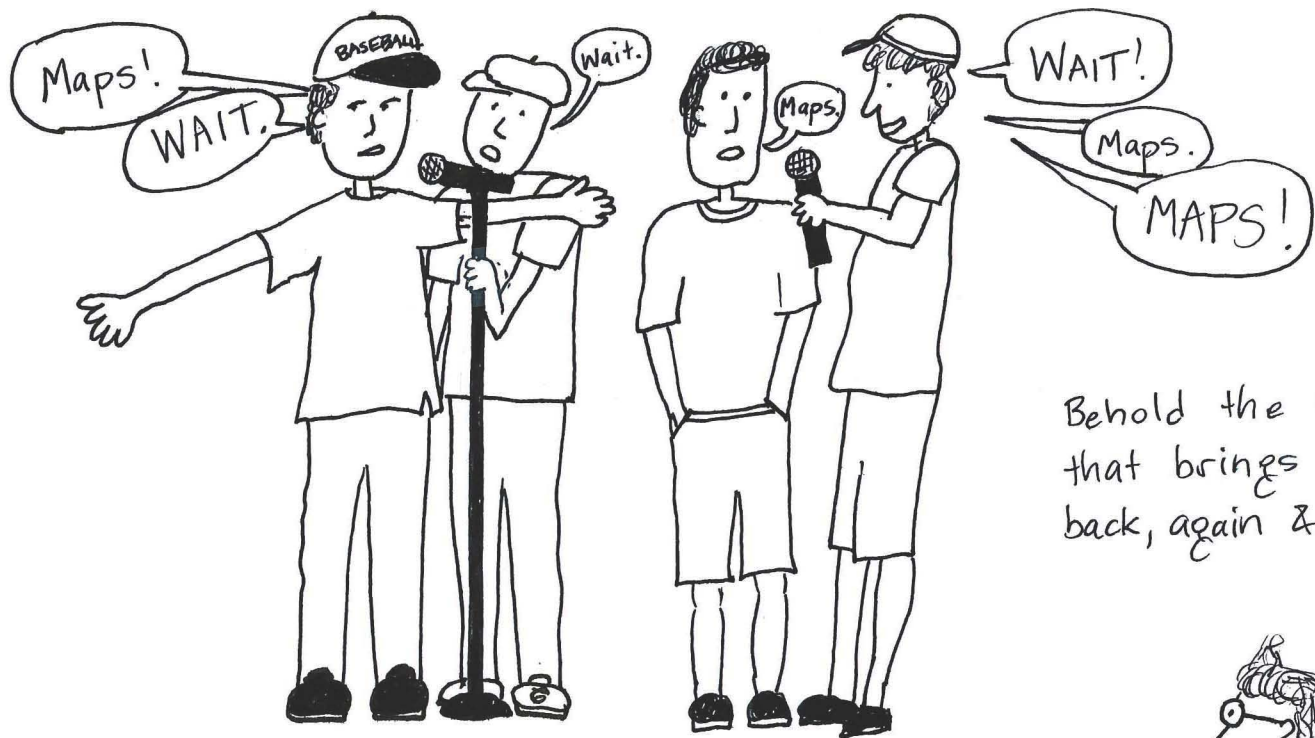
There are many different kinds of karaoke scene, AS YOU WELL KNOW.





Sometimes the whole room cheers for every performance. Sometimes the crowd is composed of isolated pods that only look up when one of their own is on stage. Sometimes there are stars who you want to see & hear again. Often there are train wrecks. Some are bigger than others. Only a few become legend.

At a recent karaoke night, we saw a group of fearless dudes get up to interpret the 'Yeah Yeah Yeahs' song "Maps." A curious choice on their part, as they clearly didn't know and perhaps had never once heard the song. As a quartet, they read aloud the lyrics as they appeared on screen, deadpan, and not in unison, with great gulping pauses between words.

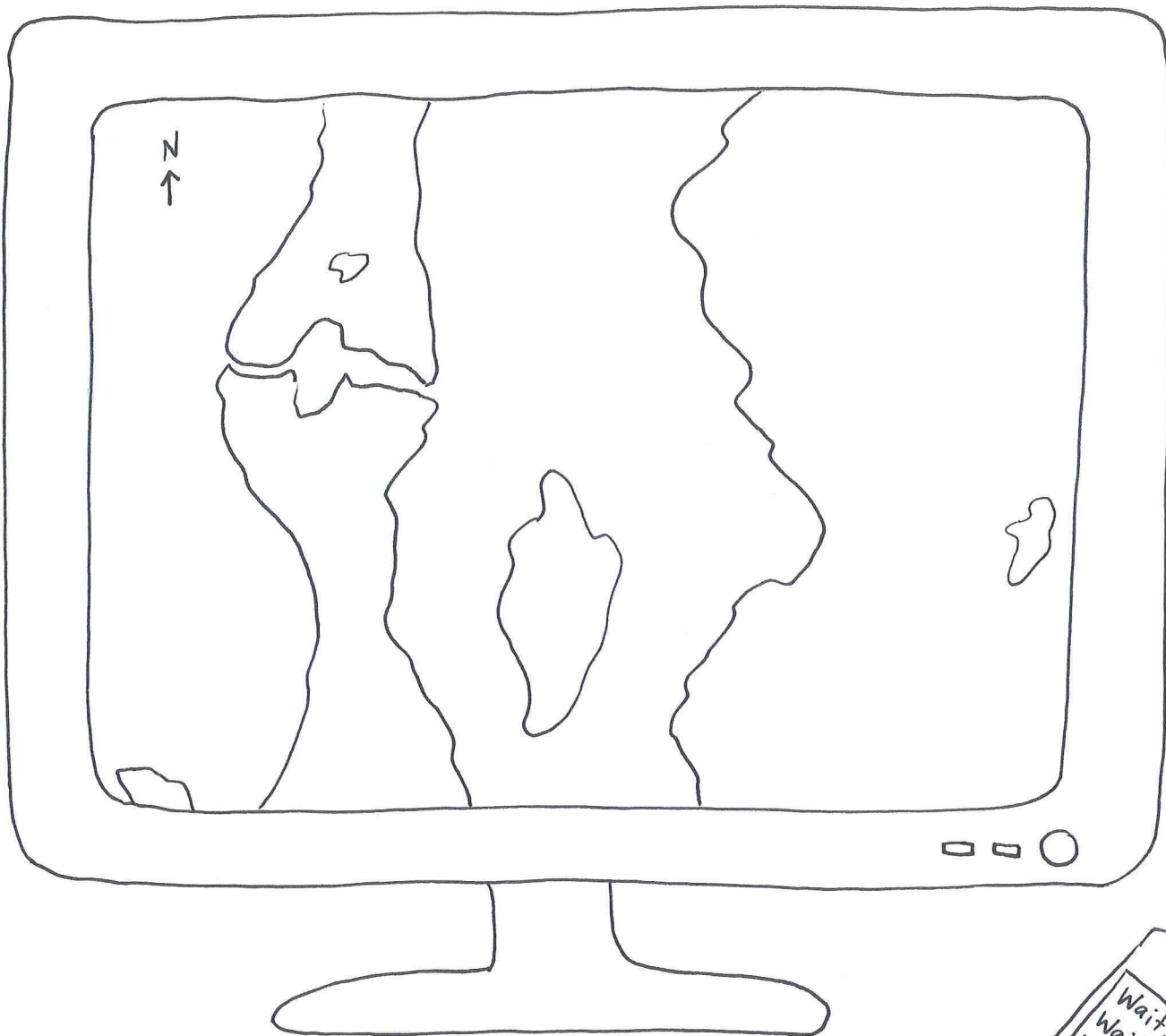


Behold the glory that brings us back, again & again.

I spend a good deal of my life making maps. It's part of my job. It's one of my hobbies.

This song - this version of this song - has become my anthem in more ways than one.



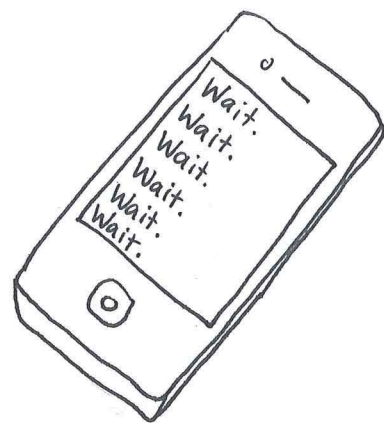


Monday, June 1st

The long last week of May
is finally over.

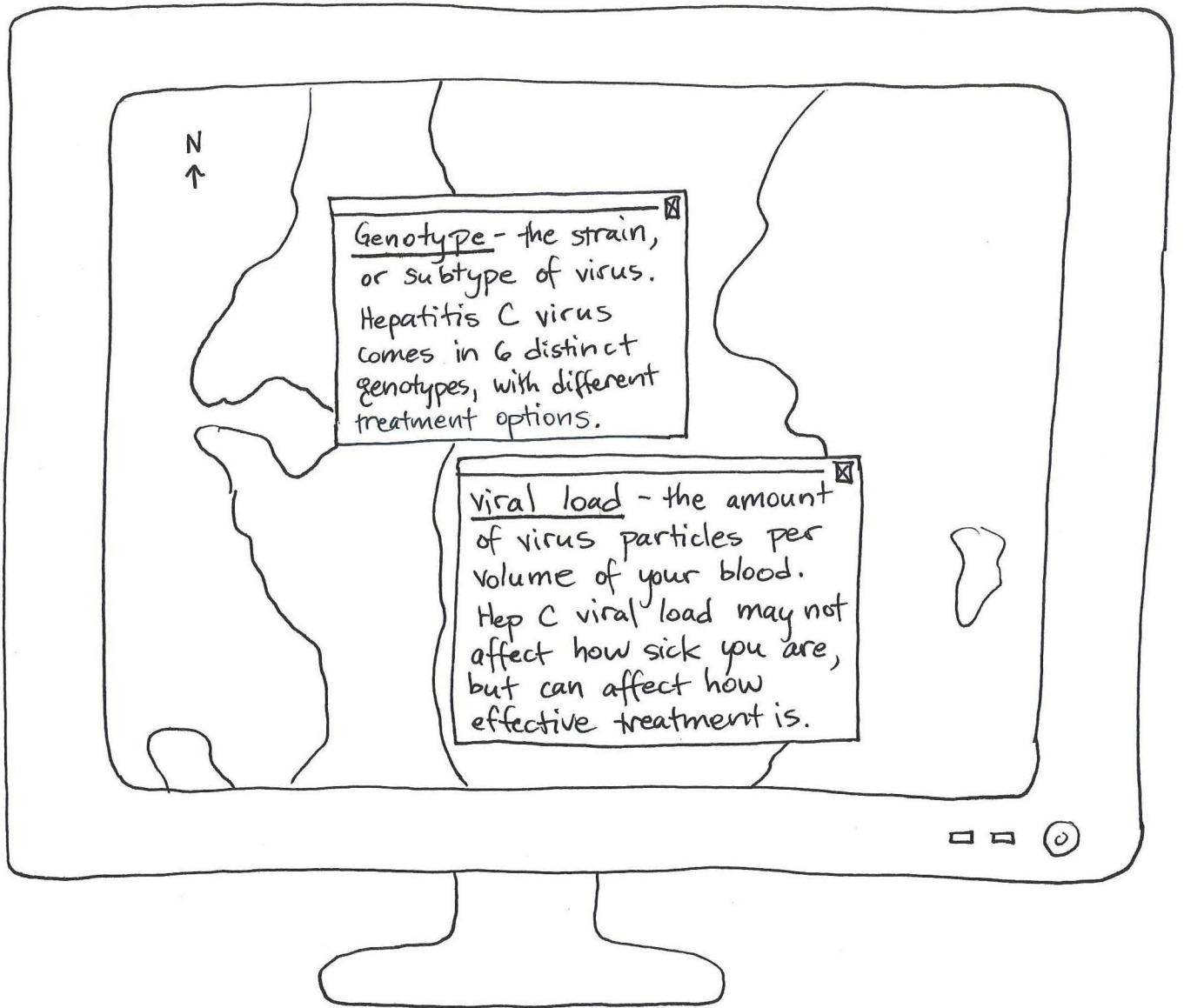
It has been 6 days and
a thousand years since
I opened that letter.

I am at work, making maps,
waiting for the clinic to call
once and for all, beyond a
shadow of doubt, with my **diagnosis**.

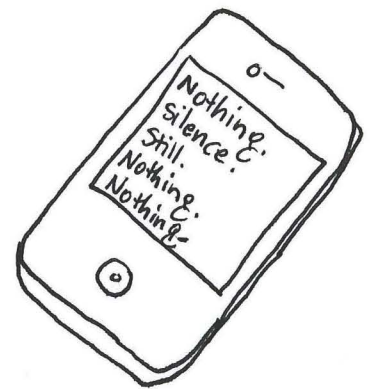


The nurse practitioner
had told me they would
call Monday morning
with two critical pieces
of information:

- 1) the genotype
- 2) the viral load.



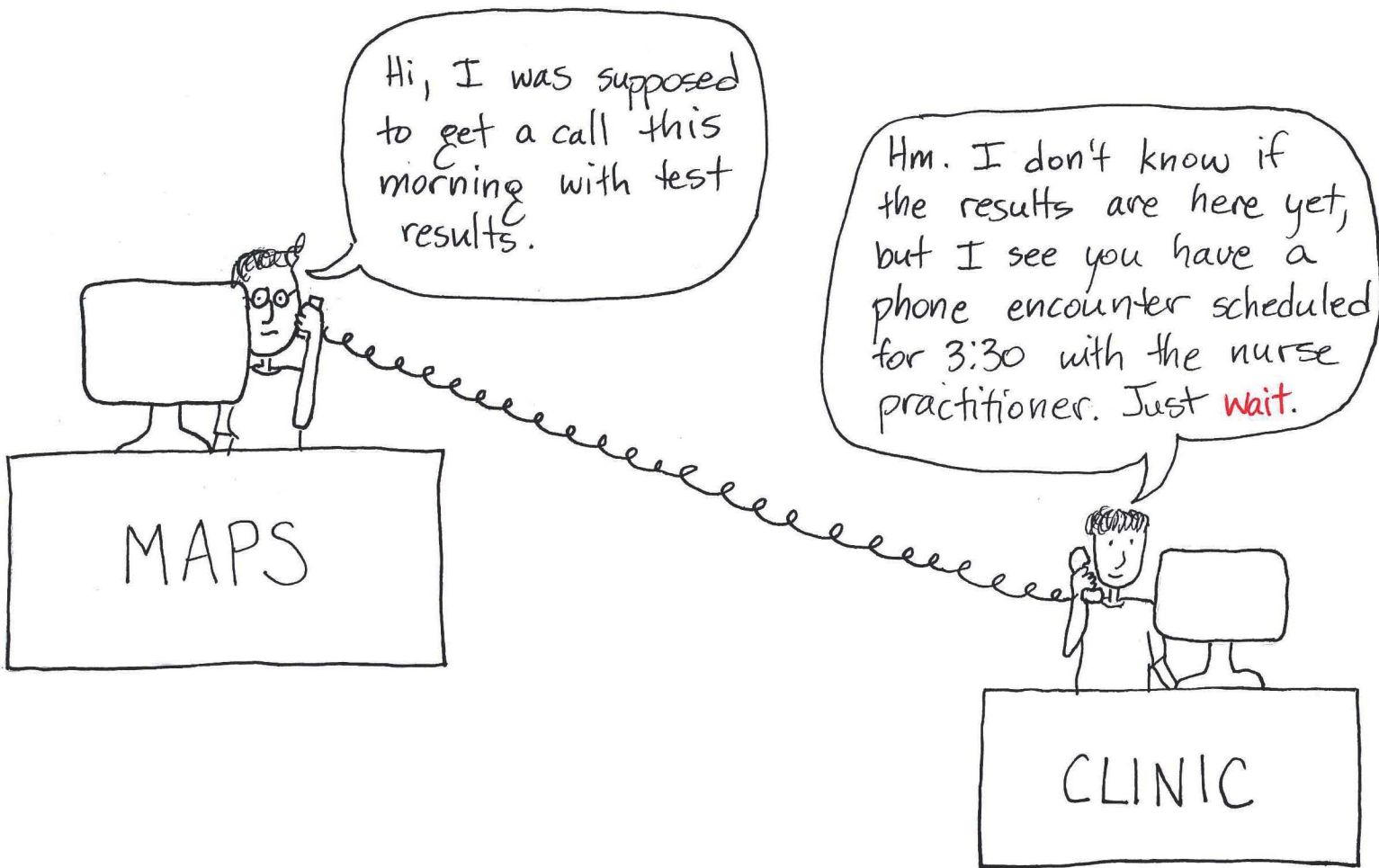
These two data points would determine how I will be treated, and how likely the treatment is to work.



Monday morning comes and goes.

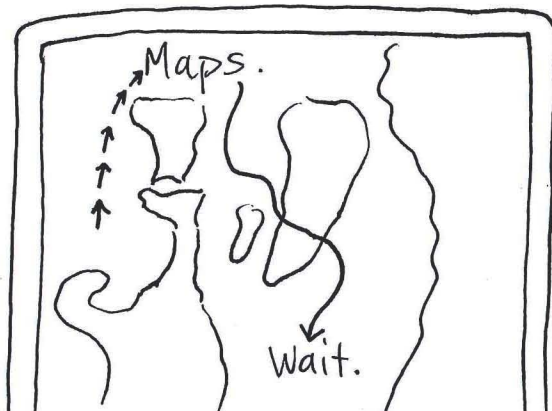
I wait. I make maps.

At 1:30 pm, I call them.

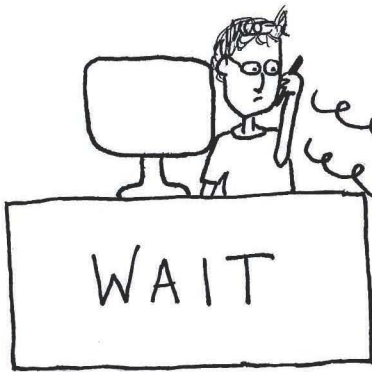


A phone encounter?
I wasn't previously informed of or invited to the phone encounter, but I'm glad to be on and know of the schedule.

I can wait another two hours.

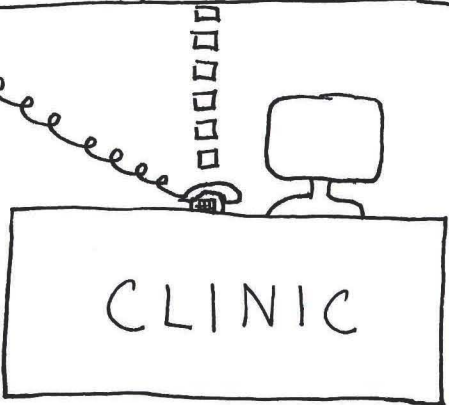


3:30 comes and goes.
At 4:00, I call them again.
I get an outgoing recording.

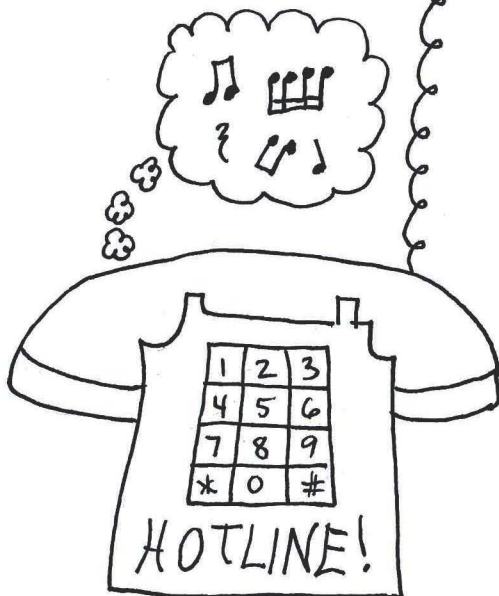


The Clinic is currently closed. Our hours are 7am - 4pm, Monday through Friday. If you have a medical emergency, please hang up and dial 911. Or call our after-hours emergency hotline.

I decide I have a medical emergency.
But not quite a 911 medical emergency.
I call the after-hours emergency hotline.



I reach hold music.



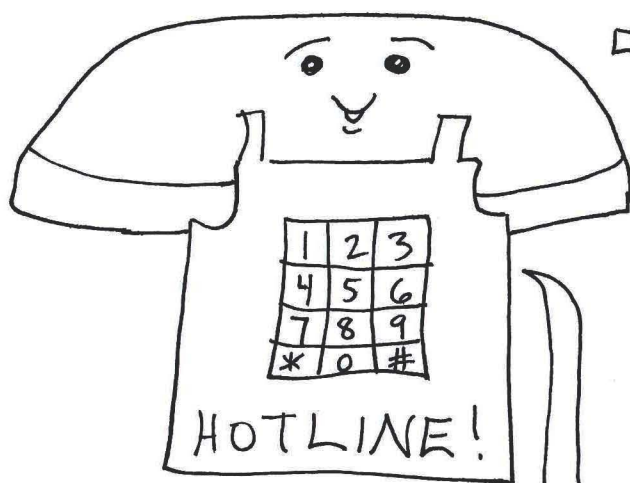
Hold music.

Who selects the hold music for the after-hours medical emergency hotline?

What do people with a more emergent medical emergency do when they reach After-Hours Emergency Medical Hotline Hold Music?

Wait.

Eventually the hold music yields to an after-hours emergency medical hotline outgoing recording.



Please leave a message and someone will return your call.

I leave a slobbering, sobbing, erratic voicemail. Possibly I curse. I am not having a panic attack. But I am losing my shit.

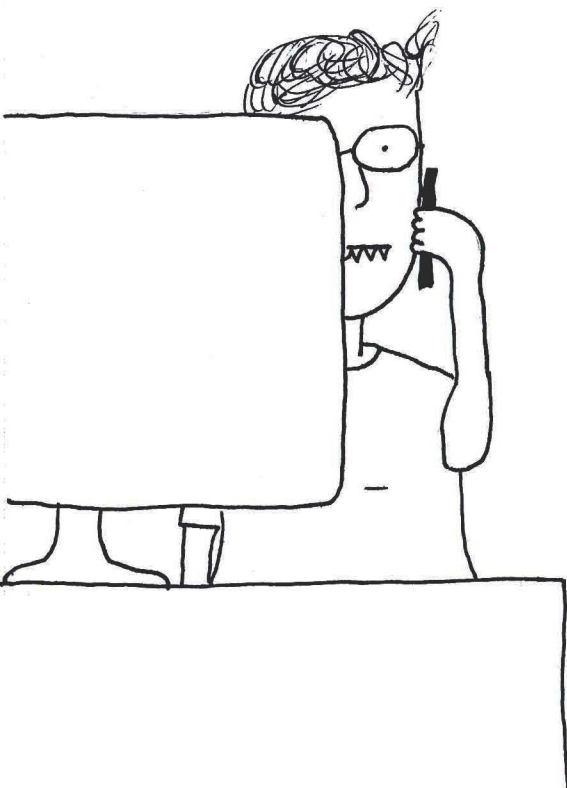
At 4:30, the After-hours emergency medical hotline returns my call.

The Clinic will reopen at 10:30am tomorrow and someone will help you.

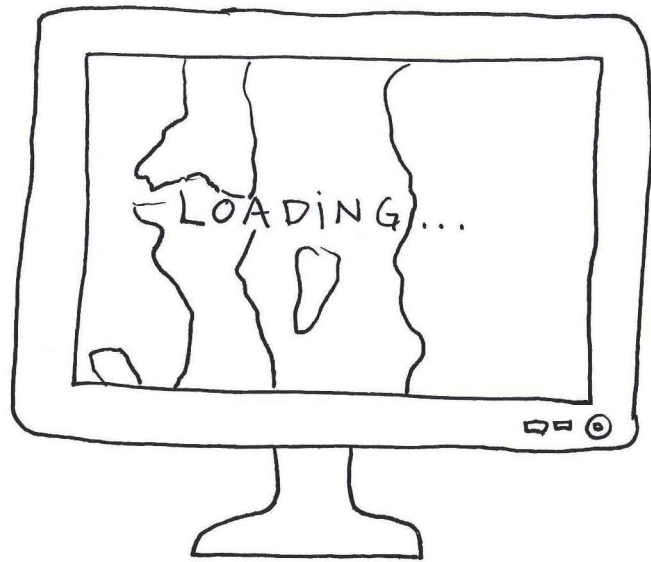
I lose it a little bit more.

I call the regular Clinic number again and leave another, increasingly erratic voicemail. With possibly increasing pitch and volume. And definitely heavier, heaving-er sobs.

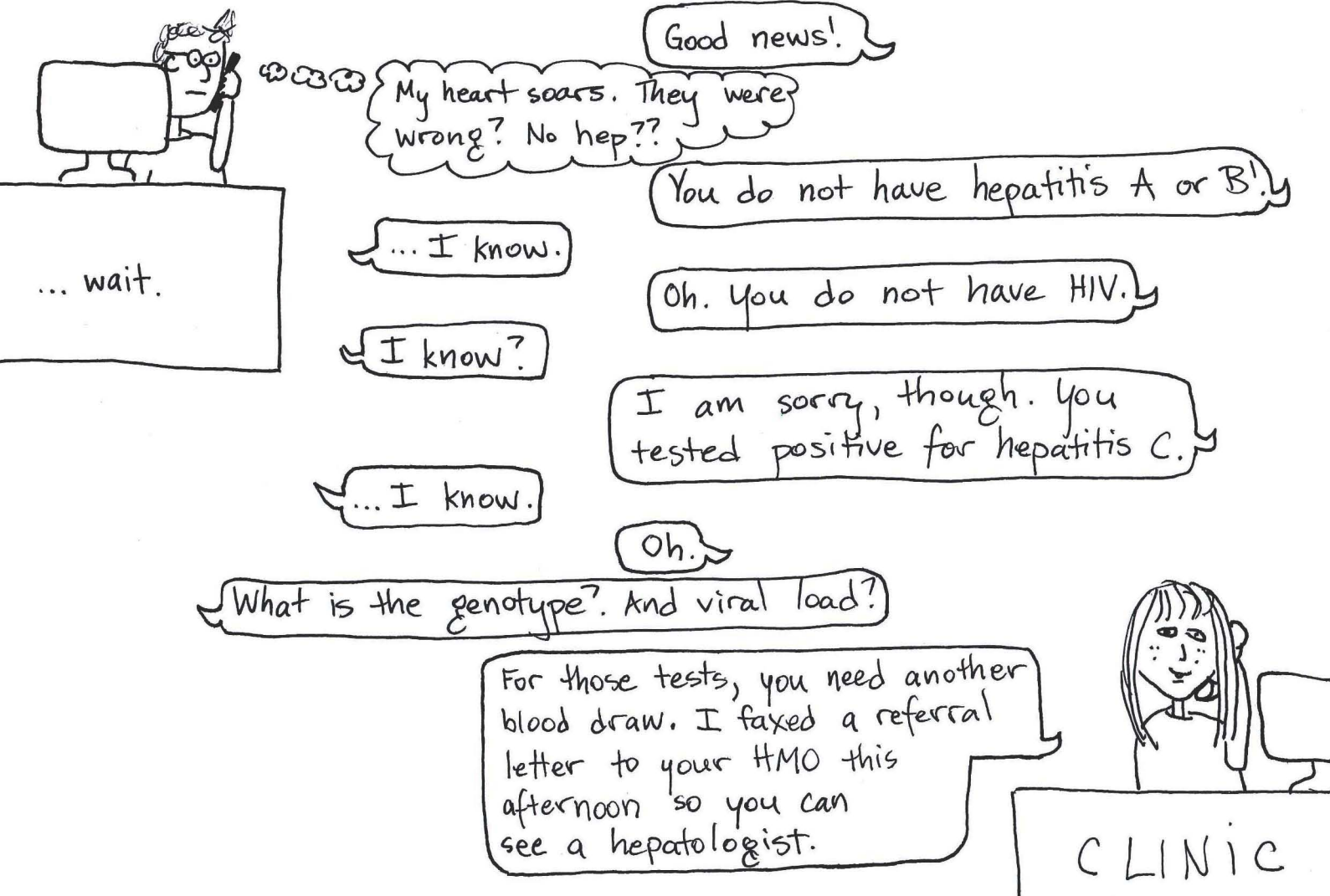
I don't intend to. It's not an act. I can't believe I will have to wait another 18 hours to find out my genotype and viral load.



Weeks and months later,
I will look back on this
as a carefree, joyful time
in which I had to wait
only mere weeks for
critical information.
Practically instantaneous.



At 5:30, to her credit, the nurse practitioner calls me. I can't believe she would call back a clearly unhinged patient two hours after closing. I deeply appreciate this phone encounter. Until she tells me all she knows.

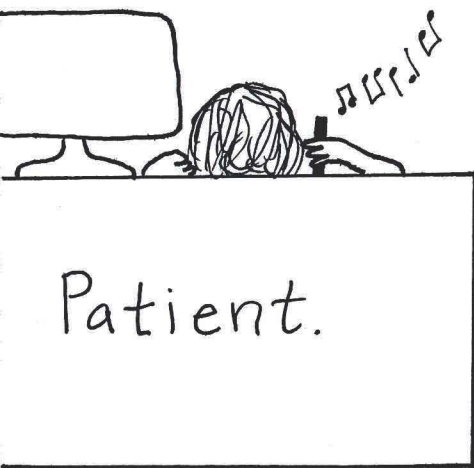


Alright.

Maybe I misunderstood everything they had said on Friday about having results on Monday.

Maybe I misunderstood everything they had said about which tests they ran.

Maybe I misunderstood everything.



My HMO scheduling office is still open for 30 more minutes.

I call to make an appointment with the hepatologist.

I get hold music.

I wait.

Hello, HMO. How can I help you?

I'm calling to make an appointment with Dr. Hepatologist.

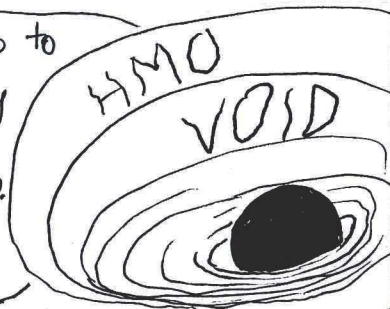
You can't make a specialist appointment without a referral.

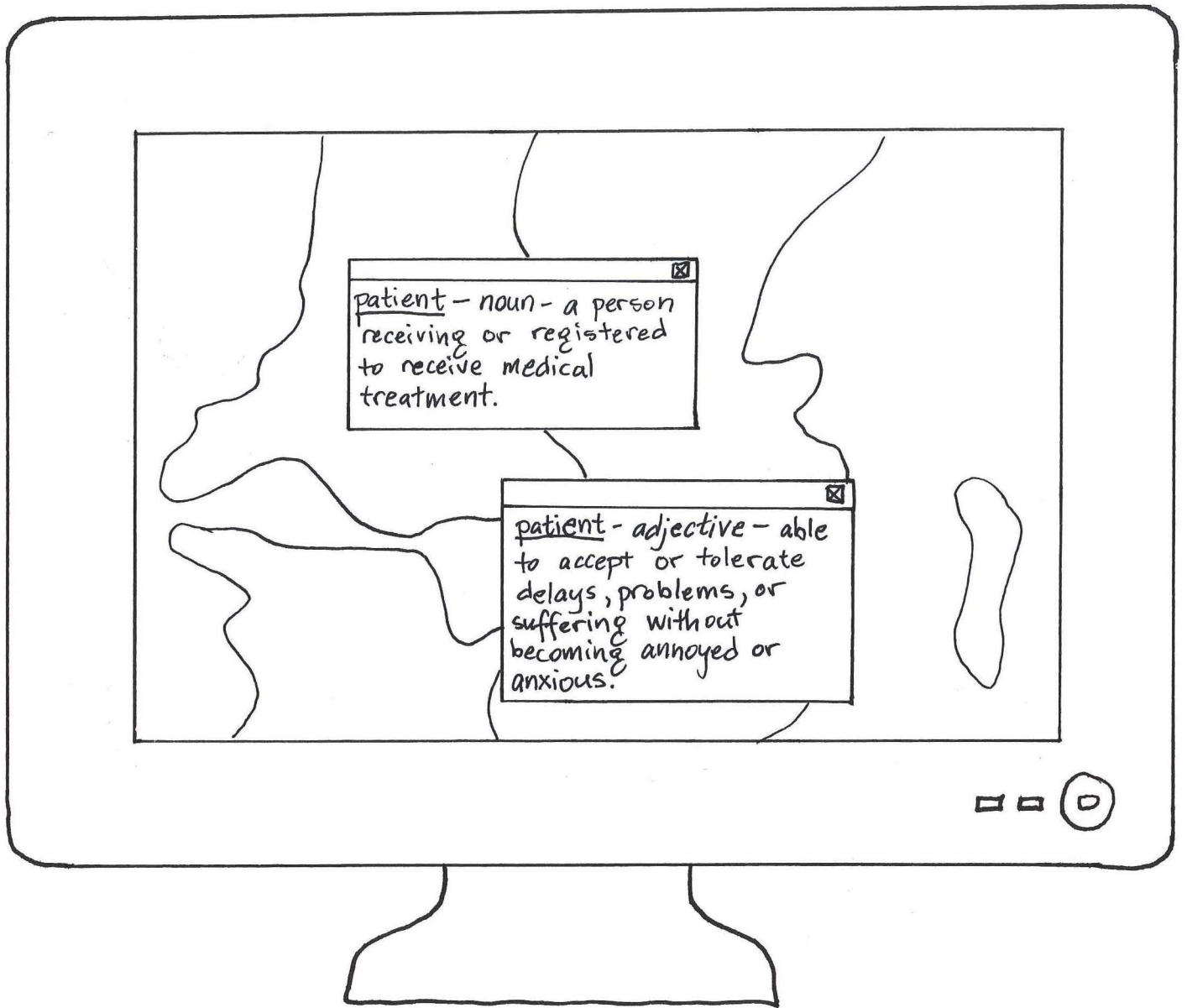
I have a referral, the Clinic faxed it to you this afternoon.

We review faxes within 3 business days.

So... I can call back on Friday to make an appointment?

Once we review it, it will go to the Medical Review Board. They review it within 5 business days to make a determination. If approved, we will call you to make the appointment.





I can't take the next step.

I can't even make an appointment
to take the next step.

I breathe.

I wait.

One thing is hanging over me
above all else.

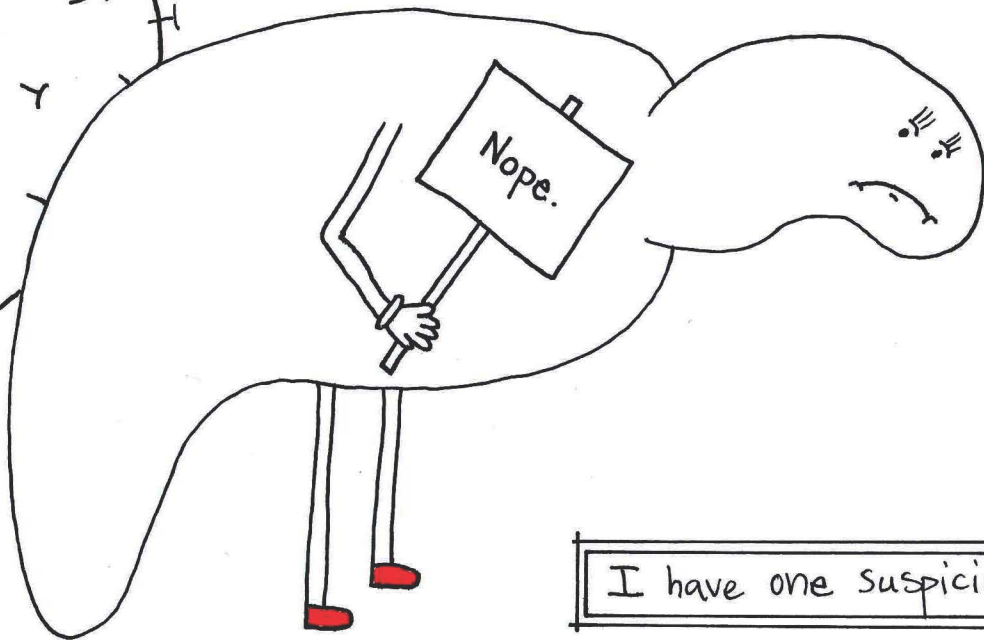
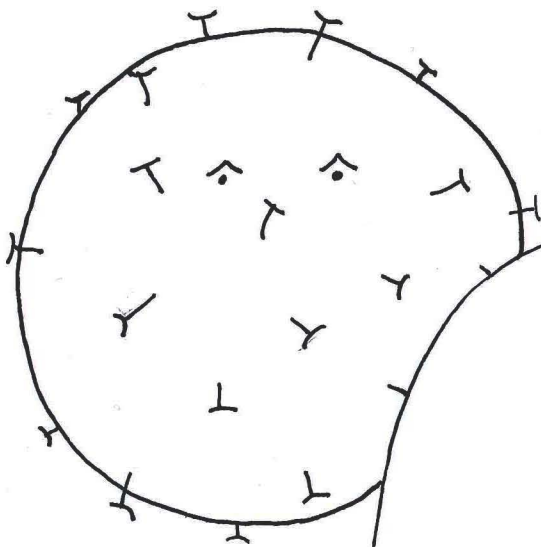
Above the virus.

Above my liver.

How did I get this?
What did I do to get this?
What did I do to deserve this?

If you can accidentally
acquire a deadly infectious
disease without doing any of
the risky behaviors you're supposed
to Avoid, then...

What part of the world is **safe**?

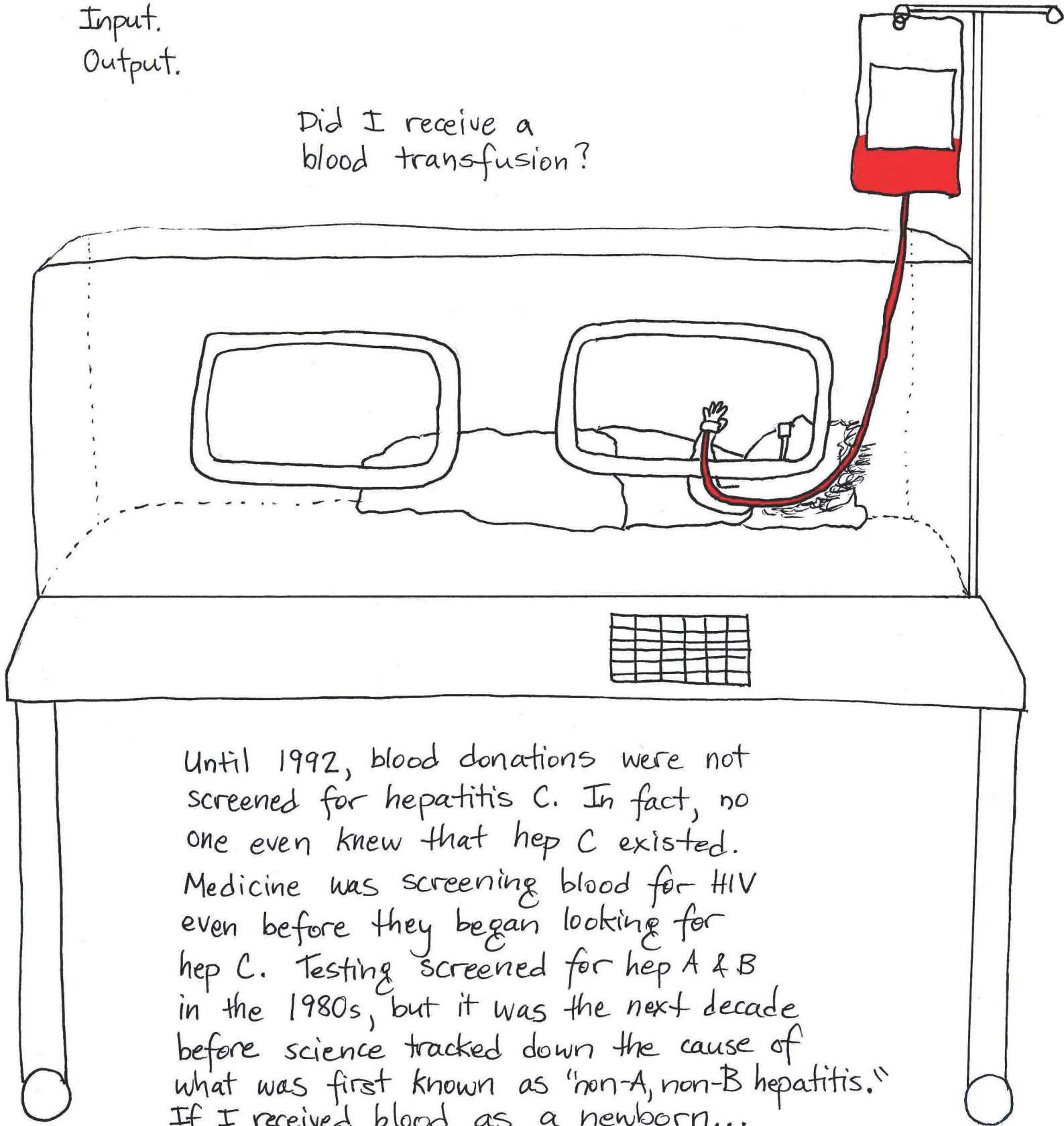


I have one suspicion.

In 1981, I was born two months premature.
I was tiny then, 3 pounds, 12 ounces.
I lived in the hospital NICU for a while.
Needles in my arms, tubes in my nose.
Constant monitoring. Procedures.

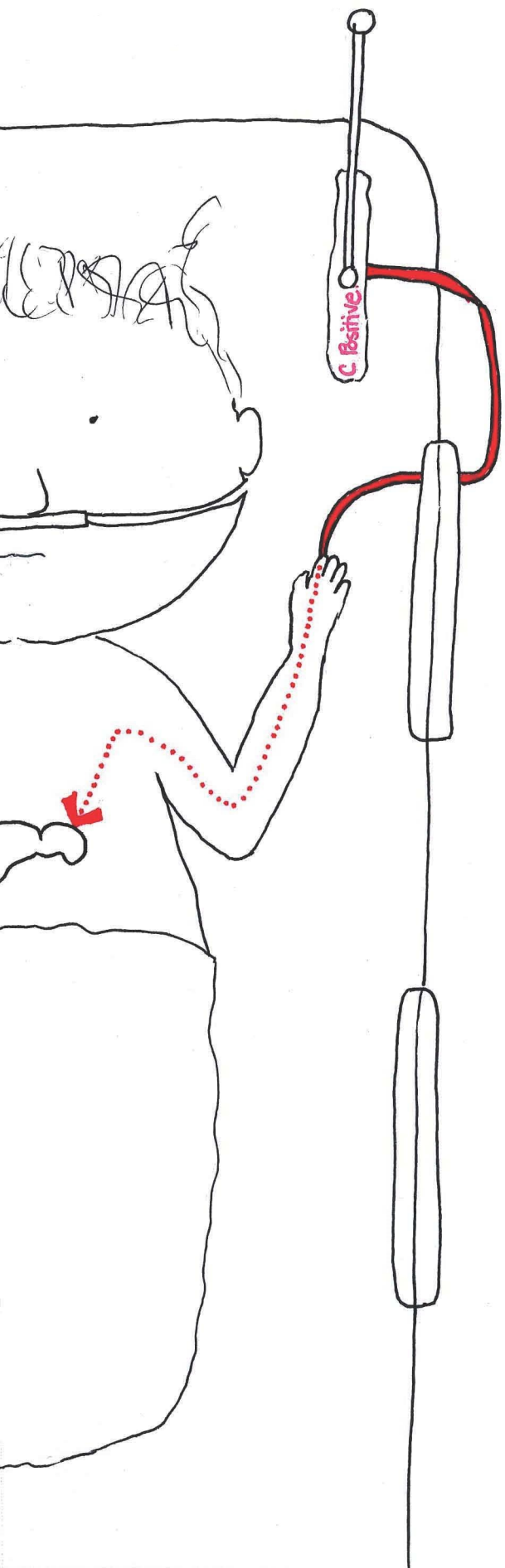
Input.
Output.

Did I receive a
blood transfusion?



Until 1992, blood donations were not screened for hepatitis C. In fact, no one even knew that hep C existed. Medicine was screening blood for HIV even before they began looking for hep C. Testing screened for hep A & B in the 1980s, but it was the next decade before science tracked down the cause of what was first known as "non-A, non-B hepatitis." If I received blood as a newborn...

... it would have been during the
high-risk, unscreened times of the
early 1980s.



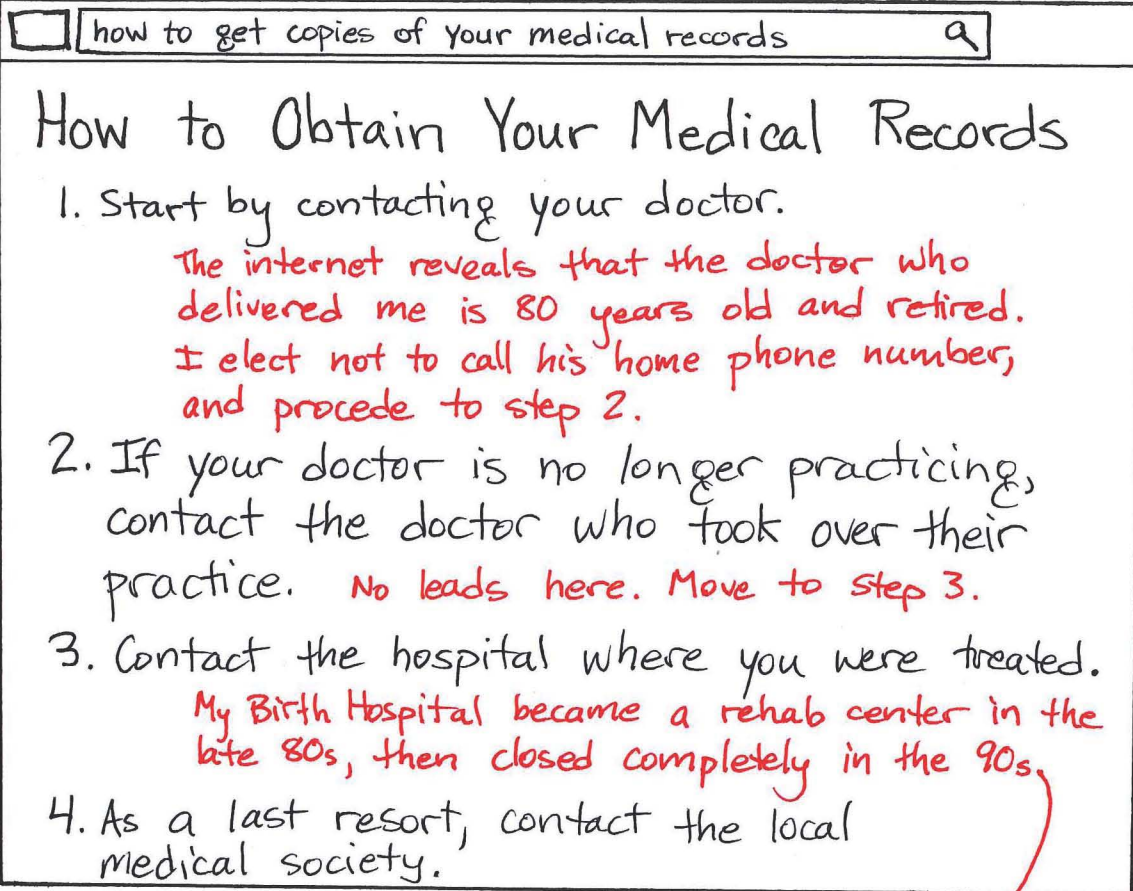
There are only two people who would know for certain whether I received blood:

My mom, and the doctor who delivered me, way back in 1981.

I'm not ready to talk to my parents yet. All it could do is cause worry, and I don't yet have any answers whatsoever.

"Hi! What's going on with me? Nothing much. I have hep C. I have no idea how I got it. I have no idea what my prognosis is. I have no idea what the treatment is. I'm just maybe super to mildly sick with a scary mystery disease that slowly kills you. OK, talk to you later!"

So I start by calling all over Texas.

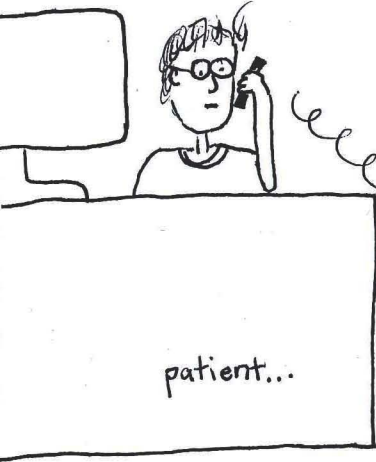


→ **WAIT.** Please note! The hospital where I was born became a place to seek treatment for addiction! To things like alcohol! and IV drugs!

I track down the website for my Hometown County Medical Society. As a last resort.

I gather my guts to call.

Hometown County Medical Society.



Hello. I'm looking for the medical records from my birth in 1981. The doctor who delivered me is retired, and the hospital where I was born is closed. Can you help me?

You will need to contact your doctor.

...The doctor is retired.

Oh. You will need to contact the hospital.

...The hospital is closed.

They will reopen again tomorrow morning. You can call them then.

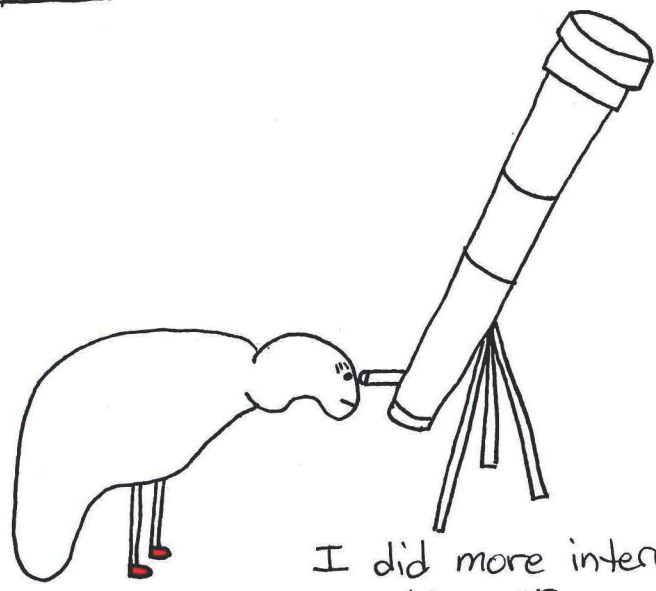
No, they are closed down. Forever.

Oh. Well, we don't keep medical records... You could call your doctor.



This is a mere snapshot of a conversation that continued for far too long.

Eventually I heard what he was saying:
I am of no help and do not wish to be.



I did more internet searching. I mapped OB/GYN offices in my Hometown.

I couldn't find who had taken over my birth doctor's practice, but I found a doctor who had been the chief OB/GYN at my Birth Hospital in the mid 80s.

I called his office and left a message for the woman in charge of medical records.

I waited until the next day. I called back and left a message.

The next day, I called back and left a message.

The next day, I called back and left a message.

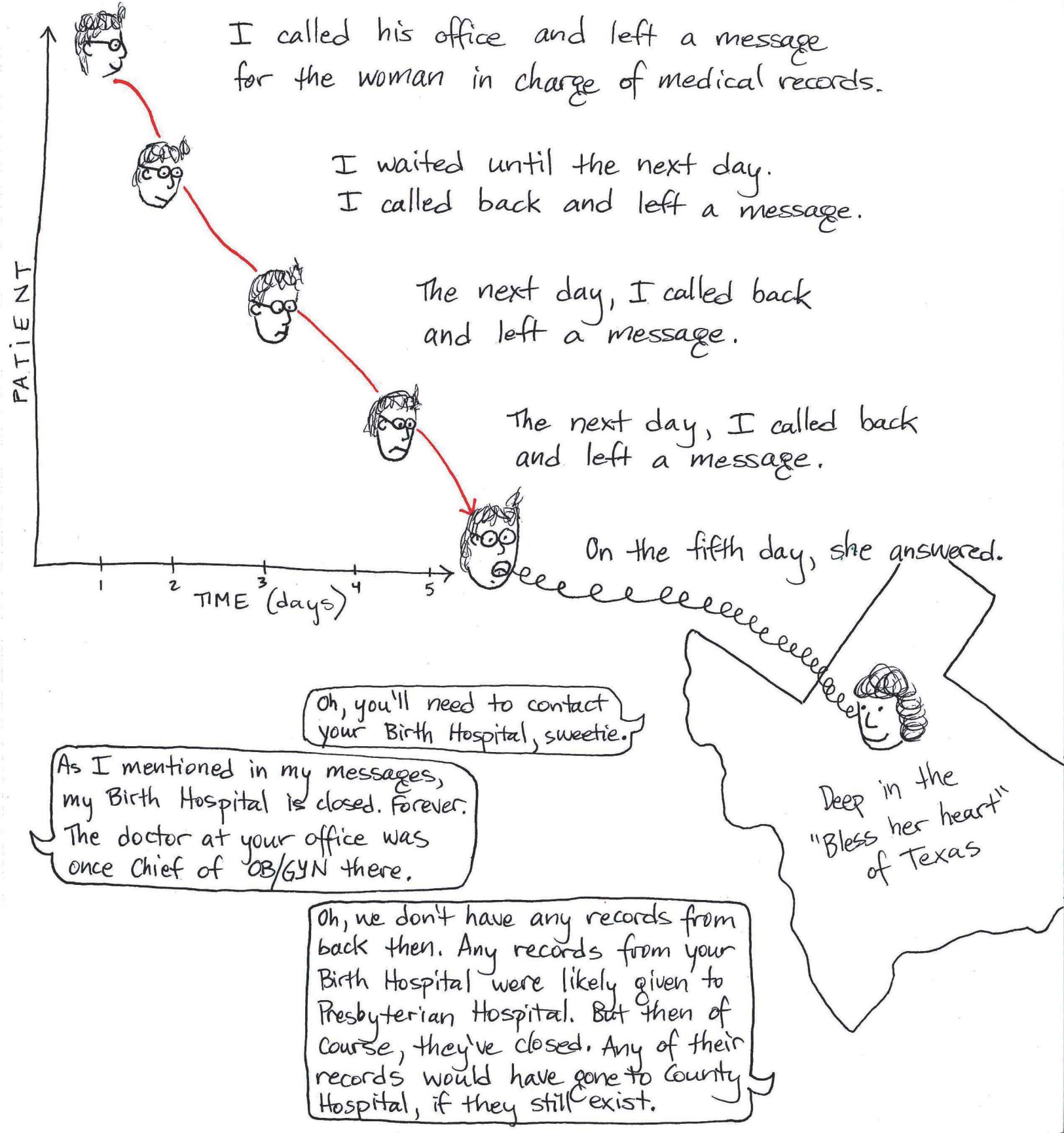
On the fifth day, she answered.

Oh, you'll need to contact your Birth Hospital, sweetie.

As I mentioned in my messages, my Birth Hospital is closed. Forever. The doctor at your office was once Chief of OB/GYN there.

Oh, we don't have any records from back then. Any records from your Birth Hospital were likely given to Presbyterian Hospital. But then of course, they've closed. Any of their records would have gone to County Hospital, if they still exist.

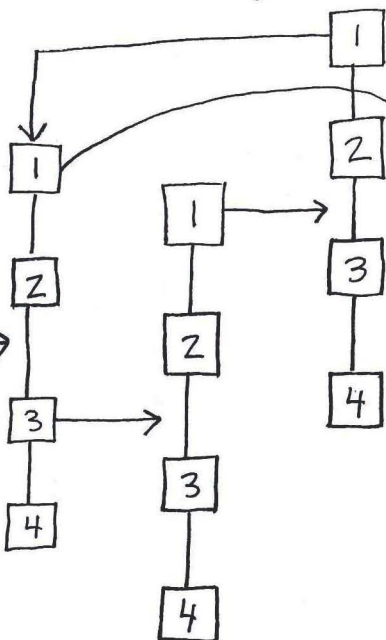
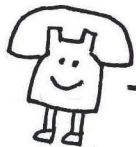
Deep in the "Bless her heart" of Texas



I called County Hospital.
I climbed multiple phone trees.

I enjoyed the Medical Records hold music.

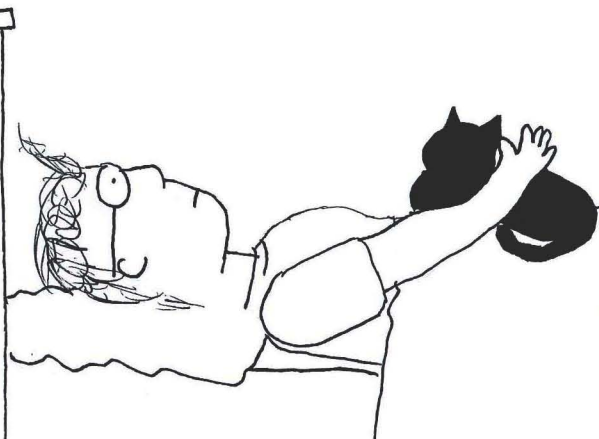
Eventually, I
got a person.



We destroy
all records
older than
10 years old.

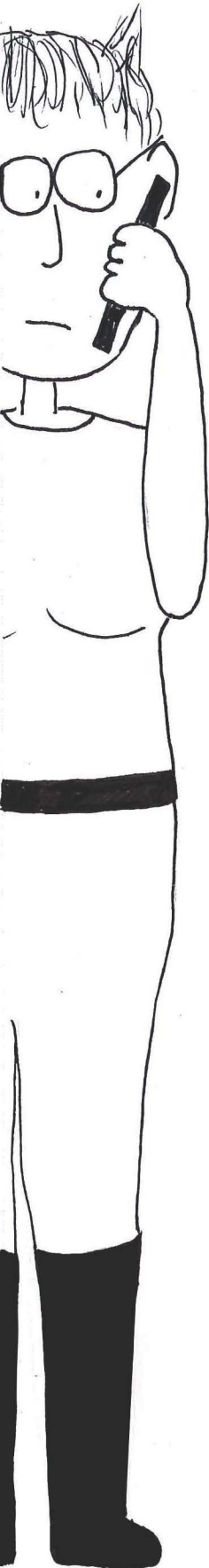
Among all the surprising news coming my way, this completely floored me. I had thought that medical records were forever, that they followed you around. They either haunted or helped you, but always existed.

It turns out that medical records are more like your permanent record in school - it may have once had a note about your 10th grade detention, but only during the time you were in 10th grade. Now, no one cares, or can help you if you care.



"How did I get this?"
will have to wait.

Until I eventually call my parents.
They answer on the first ring.



Hi Mom.
When I was born...
and in the hospital...
do you remember...
Did I receive any
blood transfusions?

Yes... more than one.
Why?

why why why

What's wrong?

wrong wrong wrong

I...
need to tell you.
I have hepatitis C.

It becomes the first time
I say it out loud.
Definitively. With a period.

Before I fully believed it,
I had to see the map.
How I got here.
How it got to me.

Now I know. I have hep C.

