

### **Concept/Idea:**

Love story involving a character with Retinitis Pigmentosa (RP)

### **Research:**

General description of RP: genetic condition that progressively causes the retina to deteriorate. Vision loss begins with peripheral vision and night vision, and, if not solely narrowing one's vision, can lead to low vision or **legal blindness**, with impairment unable to be corrected by glasses or surgical means. Often **central vision lasts far after peripheral vision**, and some can still see details for up to decades after diagnosis, though it eventually fades. [Cleveland Clinic](#)

Age of onset: Between 10 and 30 years, adequate for a YA novel with worsening progression for a teen of **15-18** highly likely. *Id.*

Diagnosis: Eye care specialist, visual field testing and retinal imaging done at an **ophthalmology clinic** (retina specialist) after an exam beforehand via an optometrist/general ophthalmologist [Prevent Blindness](#)

General Treatment: Vision aids | **Occupational therapy** | Special education/vocational services | **counseling or support groups** [Cleveland Clinic](#)

### Notes about a character with this condition:

#### **Physical**

- They would often bump into things, trip, or be considered clumsy
- Bright light could be painful to them
- They would be able to see, but if the progression was far enough, there would be no color
- Moving from a bright room to a dark one or vice versa would be uncomfortable or difficult for them
- They might have to use a cane
- They would have to attend mobility training if they were impaired enough
- They might use technology to assist them in daily activities

#### **Emotional**

- They would be tired and frustrated after long durations of focus
- Frustration at being pitied by others or misunderstood
- A sense of grief at the loss of vision and independence
- Frustration that there is no current cure
- Fear that the next day vision may be worse than it is today

#### **Social**

- They would experience some frustration with being ‘helped’ or ignored by able-bodied people
- They would be startled often from people who ‘appeared’ in front of them suddenly
- They might be misunderstood by others as being rude for ignoring them or lacking eye contact during conversations

**Character would likely be:**

- Anxious of changes in routine
- Protective of independence
- Frustrated at explaining themselves
- Embarrassed at their need to rely on others
- Afraid of the condition worsening
- Weary of their future
- Angry at being underestimated

**Drafting**

Theme of work: Self-acceptance, coming-of-age. My works utilize the growing pains of overcoming a physical challenge as a means to highlight a more universal theme such as self-acceptance or belonging.

**Chapter 1:**

~~For the last 9 years of my life, I’ve been going blind. It’s fine, though; not as though it’ll get any worse.~~ When your scope of vision is the size of a needlepoint, existence becomes very different. Right now, for example, while staring at a little leaf falling gently from a tree, I’m contemplating murder.<sup>1</sup> ¶

“Antoinette, I’m speaking to you.”

What a dumb name: Antoinette. How pompous. From grade 6 to 7 ~~For about 7 years of my life~~ I insisted my mother call me Emma from Jane Austen’s novel. But then my mother told me that I’m named Antoinette because my grandmother was some sort of feminist icon back in the 30’s, so I ‘had to keep the name otherwise I’d be giving into the patriarchy.’ And you know what? I listened to her, because I was 11. And now I have no guy friends. Thanks, grandma. You really did the good work.<sup>2</sup> ~~At least Well, we can see where that took me.~~ ¶

I blink, turning my attention away from the trees outside the hospital. In my mind, I know the colors are green. I remember what green looks like, and I can picture it. I can picture everything the way it used to be: ~~look: the~~ trickling riverbeds, yellow dandelions; the warm green of the forest outside my house, or the red of a ladybug crawling on the back of my hand. But if a leaf from those trees were to fall onto my hand right now, I couldn't tell you what color it was. Hell, I don't even remember what my own eyes looked like. I think they were hazel. Maybe I should have allocated more of my personal time to remembering that.

Oh, I forgot to say what's wrong with me. Most people want to know. They call it retinitis pigmentosa, or RP, as everyone seems to love abbreviating it. After I turned 11, it slowly started making my world fade away. And the colors from those leaves and ladybugs and creeks and all that crap? It dulled and blurred until those things were utterly unrecognizable, and I was left with what I call my "bottlecap," the little light at the end of my visual tunnel. Oh, don't worry that you'll catch it; it's genetic, and it's rare. One in 4,000 people have it, so, not to brag, but I kind of won the lottery before you did. The most unlucky lottery ever.<sup>3</sup>

~~Where did the colors go? Where did the world go, really? Well they faded slowly. Because, over the last nine years of my life, I've watched as the colors and the size of my world dulled and blurred into a scope of what you'd best call a bottlecap~~

I turn to Dr. Frett. It's a fitting name, granted that she always looks like she's about to have a panic attack, ~~sounds like like she has a screw loose~~, and also because we only visit her when something's gone horribly wrong. I smile at her politely, looking in the direction I think she should be. ~~in.~~

"I'm sorry," I start, raising my arms to set them on the armrests. "Who —" There is no armrest. "...I'm sorry, *Who* —" Okay, it was *here*. It was here last week. I falter, now very

preoccupied with this where-is-the-arm-on-this-armchair-situation. “I mean *what* —” **Alright.** I break. “*Damn* it where is the armrest??”

“Antoinette Jones!”

I can feel my mom’s stare **searing into my left ear** as I glare at the direction of my mom’s voice, **almost tasting** ~~I can hear her frazzled contrived~~ tone.

“No swearing.”

“They removed...” I hiss, “...the *armrest*.”

“New chairs,” Dr. Frett says flatly. “Last week. **Tissue?**”

**Dr. Frett is big on the whole ‘offering emotional support’ thing.**

“No thanks,” I say. “Thanks, Amy.” Amy is her first name. ~~Sorry.~~”

“~~No, no,~~ I’m sorry about my daughter,” my mom says, ~~not meaning it.~~”

I shove my arms together, folding them across my chest. “I’m going blind,” I hiss. “I can say whatever I want.”

I can hear my mom sighing from the couch beside mine (hers is nicer; they always give her the nicer stuff), but I can only see through my bottlecap at any given time and naturally, that doesn’t include most of the important things around a person. Like whether or not they’re surrounded by armrests. Or vehicles, stairs, pizza delivery guys (don’t want to talk about it) and attractive women (again; don’t want to talk about it).

The chair creaks as Dr. Frett leans forward, and I can almost make out the sympathy in her eyes. Wait no — those aren’t her eyes. That’s a painting of a banana. Where’d she go.

“I’m sorry, Antoinette,” she says. “But I think it’s time to start looking into some programs. A therapy group would be lovely for you —”

“**Therapy?**” I nearly shout. “**Ha!** I don’t need therapy. **I laugh in the face of therapy!:**”

I glance at the direction of my mother. Oh god. She ~~I cut her off. I realize that if she's~~ said it, then my mother is *definitely* going to try to force me to go, and if she does, I literally cannot escape ~~from the car.~~ I shift in my seat, laughing nervously.

“I mean,” I say, glancing in her general direction, then back. “I don’t —” I glance at her again, then drop the act, falling back against the seat. “Look, ma’am, I don’t need therapy, I have food and a whole lot of audiobooks so thank you very —”

“Mrs. Antionette Jones.”

I raise ~~one my~~ eyebrows, finally locating *le doctor*. I have my eye on her locked jaw, her lips pressed together in a practiced line. She sighs in a very rehearsed way and shakes her head.

“I’m sorry, Antionette, I really am. I suggest you begin therapy immediately ~~with others your age experiencing similar issues. Maybe journal, Start writing in a journal. Draw...~~ see a movie. Live your life —”

“Before it’s over,” I say. “Got it, captain.”

I push myself up from my chair, reaching for the edge of the table as Dr. Frett turns to me. “Antoinette, there’s a wonderful therapy group that meets on Fridays. You should join that one. I have the flyer.”

“Oh a *flyer*,” I say with mock enthusiasm. “I’ll be sure to add that to my burn pile where I take pictures of my doctors, write little x’s over their eyes and curse them with a black magic ~~only I understand.~~” ~~also destroy the names of the doctors who tried to get me to go to therapy.~~

“Antionette, *my god!*” my mother hisses almost violently. I turn in her general direction, ~~forcing a smile.~~

“Mother? Language.”

Dr. Frett interjects. “I highly recommend it.”

I turn to her. “Therapy? Me?” I say with about as much sympathy as a stab in the back. “I don’t think so.”

\* \* \*

“Love you sweetie!”

I shoot my most seething, hateful ~~worst~~ glare at my mom before shoving open the car door and stepping out into the brisk October air. I stand outside for a minute, looking blankly at the parking lot above the 1997 Toyota Corolla (how is this thing even *running?*) while I silently ~~and plan~~ ~~planning several~~ ~~nine~~ ~~methods~~ ~~ways~~ of escape. The wind picks up, tousling my dark hair, and I sigh, hand gripping the doorframe. The news hums quietly on the radio.

*“In local news, a Melbrook High School student has gone missing. Authorities believe this to be an isolated incident.”*

~~I turn around, facing the car in defeat.~~

“Do I have to go,” I say flatly.

“Yes you do,” she says. ~~Love you!~~ “See you at 6! Love you!”

She smiles. “If you don’t, it’s the feelings journal.”

I grit my teeth. “Fine” I spit, slamming the door.

I hear the automatic window roll down behind me. “I love you!”

I scowl at the entrance, looking straight down so as to not miss any steps and make an absolute fool of myself. I grab for the stairwell, missing once before grabbing onto the metal and slowly making my way to the door.

Okay fine. I miss the stairwell three times. Potato tomato.

Do I need a cane? No. I don’t *need* one. I’ll *never* need one. I have *eyes*, and they work... adequately. As long as I can see what’s right in front of me, I can see. I don’t need any artificial assistance. I’m an independent adult, and that’s not changing anytime soon.

I notice the little creature as I near the top of the stairs, even though it looks more like a beetle now and is drained of all character and color. It's upside down, struggling to right itself. I brush it into my palm, staring at its little legs as the ladybug — which obviously does not look like a ladybug in my eyes because it is so dark and colorless — doddles on my palm, and, despite my crummy exterior, I really do care for it, because it's a little, helpless creature and I can help it. I get down to a precarious squat, letting it walk off into a nearby veranda.<sup>4</sup>

I straighten myself, brushing my pants and trying to get back into my callous state of mind, and I'm so preoccupied by my thoughts that I don't notice that someone's holding the door open for me until I feel the air pressure change as the smell of an old building wafts into my nose.

Well, that was a quick way to reset the emotions. I scoff, turning back to face the asshole.

“Don't do that for me.”

Looking closer, I can tell the person is a guy. His hair is dark, swept to the side with thin-rimmed glasses and almond eyes. I'd almost be grateful for his act of service if he wasn't just doing this out of pity. He frowns.

“I'm sorry?”

I roll my eyes, shifting my weight. “I don't need your ableist pity.” I look down at his Blink-182 shirt.

“Tacky.” I shake my head and turn back, looking down at the floor again as I storm down the hall. Except, after a moment, I realize that I don't know which room I'm supposed to be going to. I freeze ~~in the hallway~~, using my limited vision to scope out a door. This attempt turns up dry.

“Ahem.”

I glare, turning my head to the side ever so slightly ~~towards~~ him. This guy doesn't need to know I can't see him; I can hear him clearer than I'd ever need to.

“It’s back here. You missed it.” He rushes his next words. “Which is okay. No big deal. But you did — well, you still missed it.”

I clear my throat, turning on one heel to face him. It takes me about 2 seconds to locate his shoulder. I look up at his face, flashing my most unfriendly smile.

“Thanks.”

He smiles back, but to my frustration, his is genuine.

“Any time.”

The **group therapy** room is quiet when I step inside, and it smells like old clothes and decaying wood. The air conditioner whirrs to life as I **step walk** towards the collection of mostly occupied fold-up chairs **currently positioned** in a circle at the middle of the room, and I can just barely pick up the smell of **some kind of** medicine.

Yup, this is the right place.

I collapse into a chair, leaning back as I take a long inhale through my nose. The people around me must either not know each other well, or not care, because there’s only the **quietest lowest** murmur of conversation happening as I brush through my hair, only half paying attention. I whip out my phone, scrolling through the **artificially** oversized apps (**thank you Apple accessibility**) as I try to find a way to look busy.

**This is humiliating**

I text Meridia, my best friend and confidant.

**I think I’m going to crumple and die of shame.**

The speech bubble pops up a second later.

**Maybe they’ll die before you do?**

She replies to my **utter** dismay. I almost choke on my own spit.

Meridia, I type wildly. **They’re not dying. Did you think that was what this was? That would mean I’M DYING TOO**

I scoff, shoving my phone back into the pocket of my jeans. This is humiliating. Truly, this could not get any worse.

“Hi again.”

Oh. I spoke too soon.

The voice of Blink-192-guy tunnels into my ears like the scraping of lead into a fresh wound. I straighten up, resting my forearms on my knees as I stare into the center of the room, where someone is coming into view; a short, skinny guy with black hair. ~~As he takes the seat next to me, I groan. under my breath.~~

“Can’t you sit somewhere else? Anywhere, really.”

he laughs quietly, making my chest simmer. “There are no other seats.” he pauses for a moment. “Lucky me.”

I can hear him sipping on a drink from a paper cup, which just annoys me more because now I know that I could have gotten a free *drink* out of this and I freaking *missed* it. Damn this stupid guy in this absolute place of misery. This is literally Hell.

“Welcome to White's Episcopal Church.”

The guy speaking is a short man, who says his piece in a voice that sounds almost pre-pubescent. “Please take your seats, or roll them into place.”

The man laughs along with a few of the other students ~~who apparently have no sense of humor.~~ I hear a few wheezes and coughs which make me frown and take a moment to actually survey the room here. There’s a girl with large glasses and crutches, someone in a wheelchair, a guy with a prosthetic leg, and a few other people who I can’t *see* the illnesses of but know they must have them because why on god’s name would they possibly be here otherwise.

Oh, am I about to look at this guy to see if he has an ailment that could even hold a candle to mine? Absolutely not. I do not care.

“Alright everyone, let’s introduce ourselves to the group.” Church guy, ~~whose~~ name ~~I come to find~~ is ~~apparently~~ Allen, launches into a speech about his battle with ~~what he calls~~

'sometimes-twitchy-left-pinky syndrome' \_\_\_\_\_, which I'm 99% sure is not actually real at all (the normies are just *dying* to be one of us, aren't they?). I'm totally not turning my head slowly, slow enough so that I can't be detected, to try to catch a glance at Blink-192-guy. I'm not interested in him or anything. I just... want to know.<sup>5</sup>

I choose to go for an incognito sort of chair-forward pull, looking down to my right as I scoot my butt forward like I'm interested in this conversation. Having my lack of visual acuity, I've become accustomed to gathering lots of information in a very short period of time. So in the 2 seconds it takes for me to adjust my position, I come to gather three pieces of information:

1. Blink-182 guy dresses well.
2. Blink-182 guy isn't slouching.
3. Blink-182 guy is missing both of his legs.

Damn it. *Damn it of course he's missing both of his legs! I should have known that he'd be at some disadvantage and I called him 'ableist' oh god I am *actually* so blind —*

"And you with the dark blue shirt."

I think he's talking about me because I'm counterclockwise left from Blink-182 and also no one else is talking. You'd think that in a place like this, with people of this nature, Allen would know better than to refer to me by the color of a shirt I literally cannot see the color of. However, because I am gracious I ~~go ahead and~~ accept the invitation.

"Hi everyone," I say, pretending to be kind as I raise my hand in a haphazard wave. "I'm Antoinette. Like the monarch who got beheaded because she was a total dick. That's me."

No laughs. No laughs for Antionette? These people are cruel.

## **Editing:**

1. Several edits were made while modifying this chapter. The character was firstly dramatized and allowed to shine with the “contemplating murder” thought I added. I figured Antoinette’s bitter, fiercely independent and resistant personality would best be shown through this frustrated thought. I also think it makes for a good hook.
2. For paragraph three, I wanted to add a reason for Antoinette’s name, considering it is pompous and arrogant. However, it ends up being very important later when it’s revealed that, just as Queen Antionette was blind to the needs of those under her rule, so is Antionette physically and emotionally blind to the needs of those around her.
3. In paragraph five I wanted to explain the condition Antionette has. In my original cut, I declined to say what her condition was because I thought it would ‘heighten the drama.’ It did not. How can drama be heightened when the reader is floundering as they try to figure out what could possibly be wrong with this main character? All other edits after are minor.
4. Antoinette needs a ‘save the cat’ moment but this one probably isn’t enough. Will adjust later.
5. I wanted to make this condition laughable and minor so that no one could be hurt by Antionette saying that she didn’t believe it was real. Workshopping it!