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A screened society

My husband hands me an open envelope addressed to him, his eyes avoiding my gaze. I've been screened since before I was born. A dozen embryos had their chromosomes counted and genomes scoured for mutations and risk factors, until I alone emerged as the most suitable candidate to be transferred into my mother's uterus. It's normal now. My mother used to tell me stories of a boy at her school. To this day, she says he's the last person born with… well, whatever condition he had. It's gone now. Good thing too. It made him look different and he was relentlessly bullied for it. Everyone looks sort of the same these days.

Slowly I remove the letter, setting the envelope on the countertop. Once I was born, they screened me again by pricking my heel. My blood was tested for cystic fibrosis, deficiencies in my metabolism and immune cells, and over 100 other conditions I can't pronounce. I'm lucky. Every single one came back negative.

When I was a schoolgirl, I was screened some more. My parents, like most parents – like me for my own child - gave blanket consent for any recommend test. Type 1 diabetes, type 2 diabetes, glaucoma, depression and whatever else was offered. They came to my school and screened me alongside my vaccinations.

My negative result came through earlier this morning. Some neurological thing, it said. Apparently starts as young as 50. Nasty stuff. I'm up for a promotion at work next year and that negative test result, saved permanently on my digital hospital record, will be an important factor.

The letter remains limp and folded in my hand. New screening tests are recommended all the time, offering peace of mind that we don't have any rare and deadly diseases lurking deep within us. We usually don't even need to send off samples, they already have them stored - frozen in their enormous biobanks. Everything is so convenient these days. Some of my friends opt-in to receive new consent forms every single time a new test comes out. When I first found that out, I laughed and asked them if they'd ever actually refused a screening test. None of them had. When I asked them what it would take, they shrugged.

Not everyone's as lucky as me. My daughter's school nearly didn't let her in. They called her "At-Risk" - the official term used to describe someone with a positive screening result. She isn't really, but she is unfortunately a carrier for a rare genetic disorder. Being a carrier means her children – my future grandchildren – might be At-Risk. My daughter herself is perfectly healthy. We made sure of that. But after spending most of our savings on multiple rounds of IVF, we had to take what we could get. I had wanted to freeze her and try once more, just to see if we could get a better option, but storing the fertilised egg would have cost almost as much as the IVF cycle itself. Besides, this one had blue eyes. I remembered reading somewhere once that there might be a correlation between eye colour and good health. So it felt like a sign, and once she was born, I never looked back. They say a mother can love any child, but I wouldn't know. And thankfully I didn't need to find out. I'd had to write a strongly worded letter to the head teacher to explain that this blip in her medical records wouldn't affect her school life at all. She has functional copies of every gene she could ever need. She could live 200 years and never get sick. So long as she ends up with somebody who isn't a carrier, we won't need to worry.

I open the letter at last, my thumb resting on the crease to keep the page flat. That's one of the great things about screening these days. You can link your results right into the dating apps. My husband and I knew each other's results before we even met in person. You can filter by gender,

height, and specific health conditions that are non-negotiable to you, although most people I know just filter out all positive results. This does have the side-effect of At-Risks usually ending up dating each other. I don't know if that's the end of the world. There's more of a shared understanding and culture, I suppose. They've more in common. And most know better than to try to procreate.

I scan the top of the page. Today's date. My husband's name. Even without dating app algorithms, At-Risks usually socialise within themselves more anyway. They even tend to live in the same kinds of places. Most of these places are on the outskirts of town. Not in a nice house in the suburbs kind of way. More of a block of flats far away from the conveniences of higher society. It's not for any legal reason, they aren't actually segregated or anything. Imagine. It's just all they can afford. Some people say At-Risks don't want to work, but I don't believe that. I think most just struggle to find places that will hire them. And I know for a fact that those that do, tend not to pay very well.

My husband's job is even stricter than mine. It involves a lot of travel. If his company employed At-Risks then they'd need special insurance and couldn't send them anywhere too remote in case they need urgent medical attention. Some people call them ticking time bombs. "Tickers". A derogatory term, but not inaccurate. Most screening tests give an estimate, but you never know when they're going to blow. Not really. And you don't want someone falling ill on company time, hundreds of miles from a hospital.

I start reading the letter in earnest, but my eyes glaze over before I reach the second line. My office does have a few At-Risks, but mostly very junior. It's not really worth it for the company to invest in promoting somebody who could develop a chronic disease at any minute. The only exception is a guy who had a false negative result – he was incorrectly told he was not At-Risk. That condition had run in his family, so he was already expecting the worst. A risk factor for heart failure. Not genetic. His parents hadn't made it past 50. When he screened negative, he was ecstatic. Came into work talking about how he was going to have the best retirement years of his life, to make up for all the time his parents never got. Locked all his savings into a high-interest bank account that promised to triple his money by the time he turns 70. I don't know if he has kids, but if he does that fortune will go to them now, I expect. He can't touch it, not in his lifetime. He tried appealing once the corrected positive result came through, but the bank didn't care. Kept citing that it wasn't policy to release locked funds based on screening test results because they're not 100% accurate. As if he didn't know that all too well.

He kept his job, at least. Pity maybe, because the bosses knew about his misguided financial planning. Either that or he'd managed to make himself indispensable in the brief time we all thought he was healthy. He is in the At-Risk office now though, down the hall from the others. I think most people know deep down that At-Risk people aren't contagious, it's just that it's a bit awkward being around them. Like having to work alongside people in poverty who all know you've just won the lottery.

It's not the first time I've thought that comparison, I'm sure I've even said it aloud a few times, amongst friends, but for the first time I notice the venom in it. I surprise myself a bit. I'm empathetic, really. I am. I used to get on well with my neighbour, Gayle. She and her partner at the time used to come round often for dinner. But when the new test came out for a late-onset chronic pain disorder, she was found to be At-Risk. I don't blame them for leaving her, really. She eventually won't be able to sleep through the night, and might need help going to the toilet and eating. Who wants to grow old with somebody like that? I do feel sorry for Gayle though. She

was so vibrant. She doesn't come over anymore. She moved to a small ground-floor flat on the edge of town. Rarely leaves the flat at all now, I'm told. Her symptoms aren't due for another 15 years but if you ask me, she may as well have developed them already. Worse still, she lost her job at the same time – the termination letter came just a day after the positive screening result. Again, companies don't want to invest time in somebody who'll end up needing extensive medical leave and early retirement. People used to retire at 60. How different the world is now, where you might not even be hired if you can't guarantee being able to work beyond that.

My eyes skip to the word "unfortunately" and I know everything I need to. I should have realised sooner. When his letter didn't arrive alongside mine earlier in the morning. There are probably extra checks and balances with a positive result.

My jaw is clenched now. I can't believe something so serious – a progressive neurological disorder – is only getting a screening test now. How has this not been a research priority for decades? I look at my husband. I know it doesn't make sense but I find myself thinking he looks sicker already. Has he always been so pale? So vascular?

My face suddenly feels hot as I read that this condition is often hereditary. They didn't have the sample they needed from our daughter yet, but a letter asking us to book her an appointment to collect it will arrive any day now. She's so young. How will she work? Who would date her? I had always wanted grandchildren. That's why I insisted on trying so hard to get her a clean genome. I read that there's currently no way to prevent this condition. If she is At-Risk as well then it will, statistically, probably come for her eventually. And if it comes for her then it will probably come for her children. A burden on my family for generations to come. All because of him and the stupid never-fast-enough snail's pace of medical innovation. Despite myself, I know I'll never look at him the same again. For the first time after receiving a screening result, I find myself angry. I thought back to my dating app preferences and wondered. If he had had this result then, would we have ever met?

Embarrassed and ashamed, I shake these feelings off but the motion springs tears from my eyes. He's my husband. He's given me twenty years of care and laughter. He's a great dad to our daughter. A good man. A healthy man, or so I had been led to believe. My lifespan extends well into the 90s. I've never wanted to be alone. My husband is due to reach 100. I didn't filter for lifespan but I secretly always liked that about us. He'll be with me when I die. What's the point of that, if he can't remember who I am?

I let the letter fall closed in my hands. Softer now, I look at my husband. He doesn't seem angry. He does look scared, but I realise he's not looking at the letter in my hand or looking up symptoms on his phone, or anything like that. He's looking at me. It's my reaction he's afraid of. I drop the letter and reach for him instead. As it falls to the ground, I push my face deeper and deeper into the crook of his neck. He'll have to find a new job. I know that already. He'd told me his company had mentioned it in an all-hands meeting shortly after the test got recommended. Zero tolerance for neurological symptoms, apparently. Too much space for work to go wrong before the culprit is diagnosed. Too risky. Some workplaces even have rules against spouses or other close relatives of At-Risks, in case they need extended time off for caring responsibilities. I don't know whether mine does. I'd never thought to check. I always believed knowledge is power, but I don't feel powerful right now.

I thought of Gayle. Even though we were close, her experience had always felt so distant. I was one of the lucky ones. Positive screening results didn't happen to me, or within a certain radius

of me. I suddenly wished I had been there for her more. How lonely must she have been. How isolated.

I shake the letter back open with new focus. I need to know everything about this condition. I had already seen that there was no preventative or cure. The letter describes the benefit of the screening as an increased awareness facilitating an earlier diagnosis. I used to think this sounded quite good, back when every test in my life was negative. Now it reads as nothing more than "you can be sick for longer". How useful is a test result if there's nothing to do about it? Even Gayle at least moved flats, knowing that stairs were not going to be part of her future.

There's still hope for new treatments to come out, I suppose. The letter says he has about 20 years before the early symptoms start. There's bound to be new drugs by then. More and more conditions have treatments now that help delay the onset. To stave off the symptoms by another few precious years. I remember vaguely a girl from my school who screened positive for something or other. To do with kidneys, I think. I don't even remember her name. She didn't have many friends. Maybe because she took two weeks off every other month to go to some research hospital in the next city over and get some state-of-the-art infusion to help keep her healthy. I remember she always came back from those two weeks looking terrible. Exhausted and drained from the travel as much as the treatment itself. Not to mention stressed from being two weeks behind on schoolwork yet again. I remember thinking, even then, that's no way to live. But what choice did she have? If she was positive, she was positive.

Twenty years. I feel an urgent need to tell myself, and my husband, how these will be the fullest 20 years of our lives. Nobody is going to have lived so much in 20 years as we will have. This is going to be two decades of bucket list activities, of constant flourishing, of making so many memories that it will take this disease twice as long to consume them all. I falter even as the words start to travel from my brain down to my mouth. I know it won't be true. Six months, sure. A year or two, even. But 20 years? That's a long time. Too long to just blow all our savings on holidays and once-in-a-lifetime experiences. We'll still need to live and work and care for our daughter. Our daughter…

If 20 years is bad, what would 50 years of risk look like for her? Doctors' appointments, medical checkups - tracking the progression like some sick parallel of antenatal care. Except instead of a baby being born, all you get for your troubles is diagnosed with a chronic disease. I wonder how my daughter feels about it. Whether the potential peace of mind is worth all the worry, the difficulties working and dating all before symptoms even arrive. I've never asked her before, whether she wants to be screened for things. I've always taken it upon myself – submitted my ongoing consent on her behalf, like my parents did for me. I'm her mother, I'm supposed to know what's best. For the first time, I doubt whether I do. For the first time, when that letter comes asking for her sample, I don't know what I'll do.