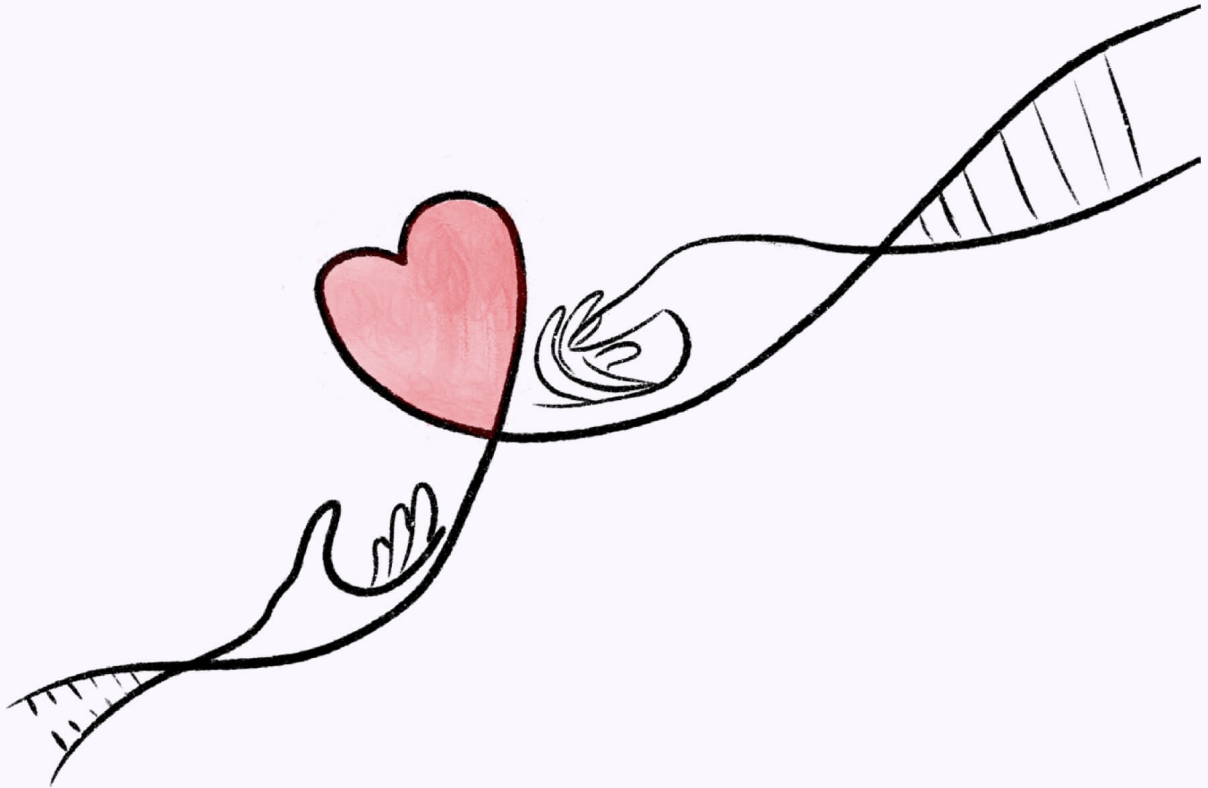


CHRISTELLE LEROY

*Come on, we're
stronger than disease*



Christelle Leroy

Come On, We're Stronger than Disease

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Foreword

January 10, 2024, the date on which the first words I wrote here entered my mind. We are a few days after the announcement of the discovery of the mutation you carry on the CUL3 gene, after almost ten years of diagnostic wandering. To cope with this announcement, I feel the need to put down the words, addressing you Nathan, because this is your story, our story. I need to tell you how much I love you, how happy I am to be your mother, and also how scared I am, and how brave, strong and impressively combative you are. Don't ever forget that.

I also feel the need to explain to you all that we're going through this together, and to shout to the whole world that your fight is hard, but so beautiful. I want to shout our pride from the rooftops. I want to tell our loved ones that, even if this trial of life is frightening and unfair, they can rest assured that we'll keep fighting for you no matter what. And then this light, and this strength, that you have within you, they are so beautiful, that they deserve to be shared, to perhaps spread to the people who will read these pages.

Putting these emotions in writing is also a response to my need, for once, not to have any feedback, not to have anyone's opinion, but just to name my own reality. This reality that I'm alone in, and that your father is probably alone in. It's a reality that despite all the love and support we receive from those closest to us, in the face of the tsunami of accepting your disability, we have to cope with our emotions alone. Faced with the fear for your future, faced with the ten thousand questions we ask ourselves, we're all alone. And at the same time, Dad and I, though close-knit, experience things so differently. We're there "for each other", "with each other", but our emotions are sometimes "next to each other".

What will this "text" become? A diary? A tool to help me accept what I refuse to accept? A record for Adrien and you of our history, but above all of yours, of your brotherly history? A book, if I dare presume to be able to write one (and even more presume to think it could sell)? I don't know, the only thing I know today is that I feel the need to put these words down in writing (and that it might give a rest to all the kind ears I have around me).

And what about you, Nathan, will you agree? Will you be angry with me for exposing my emotions in this way, offending your modesty? Or will you be proud? Or will it make you want to tell your own story one day? To explain what it's really like to live with this disease when you're a carrier?

Today, I don't know. I only hope that through these pages you can at least realize your value, your strength, and the richness you bring to our lives.

Once upon a time

December 20, 2023, "Nathan carries a mutation in the CUL3 gene".

Almost ten years ago to the day, I found out I was pregnant with you, and now here we are in the geneticist's office. You're carrying a genetic mutation that, until recently, even research didn't know existed. A moment suspended outside time, as if I were outside myself, observing the scene. I struggle to understand what the doctor has just told us, but then I realize, and the shockwave hits me. After almost ten years of diagnostic wandering, false beliefs, misunderstandings and battles to accept these "handicaps" we didn't want for you, we finally have the answer to all our questions. What's next?

But first things first. So here's your story, the story of a family who decided that despite the hardships, illness wasn't going to ruin their lives, but rather give them even more value and power.

This story is my very own fairy tale. So this is the initial setting for your story, for Adrien's story and yours.

Once upon a time, there were two people who lived in Normandy. One, a quiet guy with a passion for rocks and volcanoes, who had spent five years studying geology in the north of France. The other, a girl who couldn't stand still, and who had spent three years studying nursing in Lower Normandy. It was the time of the competitive entrance exams for the IFSI (Instituts de Formation en Soins Infirmiers), and the only exam I had to fail was the one in Haute-Normandie, where Dad and I come from. But wait a minute, life's a funny thing, and this detail may well have played a decisive role in the birth of both of you.

So we don't know each other, your father and I, we each live our own lives. When we finished our studies, we returned home to our parents in Haute-Normandie at the same time. We both had the same goal: to start our working lives. We were both already working when, one evening, he found himself on a famous online dating site. And me, that same evening, on the same site, I'm bored out of my mind, so I do something I rarely do: I decide to make the first move by talking to someone, and my eyes fall on him! I see his photo, his face speaks to me, but above all his profile: he too, having left the region for several years to study, finds himself with a network of friends scattered across France, with no real acquaintances left in Normandy... Like me! That's why, if I'd had my competitive exam in Haute-Normandie, you might not be here today: his profile wouldn't have matched mine, and we might never have spoken. After that, it's

simple, it's a match made in heaven.

A few months later, he loses his job due to redundancy. He tells me that what he does is too specific and that he won't be able to find another job in the region. Never mind, I've given up long-distance relationships, but with him I feel it's different. Life with him is simple, fulfilling and fun, so I don't let him go off on his own. I don't ask him if he wants me to follow him, just: "Shall we take one or two flats?" He answers *one*, even though, before he was laid off, he thought it was premature to take an apartment together, when we were already spending all our free time together. And so, nine months after we met, we moved to Belgium, where he found a job he liked.

The years go by, proving that we work well as a couple. Our characters are diametrically opposed. He's calm, gentle and organized when it comes to his projects, whereas I'm all over the place, making noise, getting in the way and making a mess of the beautiful itineraries he organizes for us on our trips. For him, emotions seem to be a concept he's only vaguely heard of, while for me, they transpire from every pore. A fine balance.

We're getting married, which he didn't necessarily need, but he knew how much I dreamt of it. I waited and got a proposal worthy of the most beautiful films. He has no desire to become a father one day, but he knows that I can't imagine my life without children. So, after taking a few years to build the two of us up and travel, he's ready for the next step: building our family. Here we go: mission baby! Ten months later, you were here.

So there were two essential decisions: the first, mine, was to hang on to him, wherever he chose to go to work. The second, ours: to cross the border. Unbeknownst to us at the time, this would lead us, a few years later, directly to where we needed to be: in "THE" specialized school system you'll need (far be it from me to appear controversial, but when it comes to disability, the Belgian system is well ahead of the French, as we all know).

This is the starting point of our adventure.

My pregnancy, your birth

I'm pregnant, the happiest woman in the world

December 24, 2013, today's the day I'm supposed to get my period (nice to meet you dear reader, I'm Christelle, we'll get to the heart of the matter straight away, those who know me well know: I share everything), but I can feel it in my body, something's going on. I can't wait to find out if I'm overdue, I want to give myself the best Christmas present in the world, so a little pee on a stick... And bingo! I'm pregnant, you're here!

A waking dream!

For the first few weeks, the potential anxiety I'm carrying has a field day, and I worry. Will you hang in there? Is your little heart beating normally? Are you moving well?

I worried until one day I was so terrified that I hadn't felt you move (even though your movements had only been physiologically perceptible for a short time), that I ended up in the maternity ward. There, a kindly midwife set me straight, telling me that I had to stop worrying, that you were fine and that I had to pull myself together so that you didn't feel my anxiety.

Well, thank you! This tightening of the screws is just what I needed to content myself with savoring my happiness. Without me even knowing it at the time, it gave me a few days of grace before the first real scare.

The very first alerts

Let's take a moment to explain to our readers (because in your own way you wrote this book with me) how the rest of my pregnancy unfolded.

We're 4 and a half months pregnant at a regular monthly follow-up appointment. My gynecologist picks up her modest ultrasound machine so we can say hello, and there she is alert: "I don't know if it's just a little baby, or if there's a problem". The first justified concerns begin to surface.

My mother had pre-eclampsia when she was expecting me, I was born a little earlier than expected with a low birth weight, and I had to spend some time in an incubator at birth. Would history repeat itself?

Month after month, the monitoring continues. At just about every one of the many ultrasounds we had, the two main doctors treating us became more and

more worried that something was wrong. I don't know why one gynecologist, whom I've only seen once, thought everything was fine when the alarm had already been sounded. We still haven't figured out what she missed; her only concerns were my sugar cravings, which I had under control, and the risk of me gaining too much weight (if only...). By the way, Séb, the extraordinary dad in this story, was also asked to slow down on the sugar, even though he hadn't asked for it and doesn't really like it. At least we still laugh about it today. So, whatever this gynecologist thinks, he's not putting on weight normally. The more the ultrasound scans go by, the further his weight deviates from the norm. The concern is growing.

Summer arrives. My gynecologist is about to go on vacation, and she says goodbye to me, pointing out what we both know: she hopes to find me still carrying when she returns, as I'm not due until September, but she doubts it... My follow-up is then taken over by the gynecologist who gave me my first and third morphological ultrasounds.

At around 7 and a half months, I started to lose blood and went to the emergency room, where I was kept overnight. No particular worries for this small loss of blood, but we took the opportunity to check the weight and height again. Not good.

A worrying end to pregnancy

After that night in hospital, as I was about to leave, the gynecologist stopped me in the hallway to share his fears: "Your baby is really very small, I don't know if his heart will be able to withstand the contractions when he gives birth." I remember bursting into tears, standing in the middle of that corridor. I can still see the nurse in charge of the department rushing over to the doctor and me to take us to her office so that I could digest this announcement and cry out of sight. At that moment, I was so afraid of losing him, especially as our close friends had just lost their baby a few days before birth: a nightmare almost at hand, it was terrifying. So the doctor's advice was to lie down or sit up as much as possible.

From then on, I spent my days on the couch, which became a precious ally, no matter how frustrating or how much I wanted to move (I once managed to stand up without even realizing I'd stood up, sitting was a challenge for me...). I have to go to the hospital every other day or so: blood test, monitoring, bonus morphological ultrasound. We discovered that my uterine arteries weren't irrigating him properly. During a morphological ultrasound, the gynecologist

warns me: "We'll try to hold it as long as possible, but I doubt we'll make it to 37 weeks."

Triggering your birth

The following week, same place, same exam, we have an appointment with you champion, to say hello to the ultrasound machine. I've left my computer on at home, so I'll be back on the couch when I get home 1 hour later (it's supposed to be quick, and we live very close to the hospital, which will soon come in handy on many occasions, by the way). Your father and I arrive at the gynecologist's office, I take a seat on the examination table, he starts the ultrasound, and the verdict is in: you're really in trouble. You've hardly gained any weight in a week, the blood exchanges between you and me are getting even more disrupted, and it's becoming dangerous for you. You need to be born! At this point, the doctor estimates your weight at 2 kilos; three days later, at 36 weeks, you'll be born at 1.640 kilos with skin on your bones.

A new anecdote (yes, you know, I love putting them everywhere), the one won me the choice of the spelling of your first name. A few days before this exam, Dad and I realized, almost by accident, that we didn't spell your first name the same way - Dad spelled it "Nattan". At the time, we said we'd talk about it again in the next few days, except that in the meantime, the announcement of the induction arrived. When the doctor informed us that I'd be going straight up to the maternity ward, I looked at your father and thought: "We haven't discussed the spelling of his first name. The result: he gave in in a second, and it was "Nathan". He's always had a sense of priorities, your father, and right away he says that the urgency of the situation and the fact that I don't have to worry about it take priority over the choice of spelling for your first name (having said that, he'll later admit that it was the one to choose).

With that, we're off to the maternity ward. But from the moment the doctor sends me off to induce labor to the moment you're born, it's over 80 hours. Despite the hormones, hardly any contractions. My body doesn't give up, you stay nice and warm. On the first day, the doctor decides to stop the hormonal stimulation at the end of the day, because he's worried about your state of health and doesn't want you to be born in the middle of the night with limited nursing staff. The second day, still nothing. On the third day, he decides to pierce the water sac: a few slight contractions, then after an hour or two, nothing. After the water has broken, a stent is put in: you're still in my belly, and already they've come to bother you, and you end up with little electrodes stuck to your head to