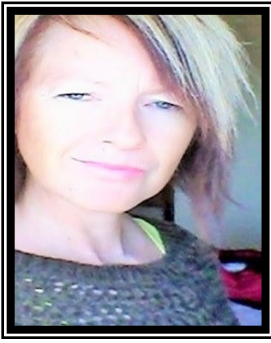


SOPHIE'S STORY: "THE FIGHT OF MY LIFE"



1998, only a few weeks into my master's degree as a career counselor, my two year old son with me, I began to feel fatigued and dizzy. Pushing myself to the limit as usual, I finally decided to have myself checked at the hospital in Moncton. I couldn't even drive my car so my roommate offered to follow me as I drove. At the hospital, with low

blood pressure and not a good color on my face, they found that my hemoglobin level was 60. After being hospitalized and having all the tests they could do, they found nothing.

After a few weeks of difficulties, my son not adapting, and always feeling sick, I decided to finish two courses in my masters program, and let go of my dream. I joined my partner in Grand Falls NB, and began the learning of "letting go." With a motivation like no other, I found a job in my field, BA in psychology, within a few weeks. Working my ass off with 3 years of traveling, replacing everybody and saying yes to every opportunity in the department, I reached my goal, a full time job. I achieved this in 2001, but needed to travel 45 min day and night. At that time, nothing could stop me, bring it on!

I was constantly being followed by doctors and specialists because of the low iron and hemoglobin, and having test after test after test and still, NOTHING, they found nothing. The battle continued and so did the tests!



I gave birth to my second boy in April 2003. By Christmas time, taking care of everybody else but me, I was starting to feel dizzy again, and my heart was pounding like hell just doing simple tasks. But, as all mothers do, I was telling myself, "it's nothing, it's nothing." At Christmas time my sister-in-law needed to face the facts and tell me, "Sophie your

skin is yellow." I told them, "OK, I'll call health care by phone when I get home." They told me it'd probably be a good thing to get to the hospital to get checked up. So, after a few days, there I went, with my baby in my arms, to the hospital. When I entered I could feel all the looks towards me. When the nurses and doctors saw me they said I really didn't look good, and found that my hemoglobin level was 60—wow again. They didn't know how I was still standing up but you know what, they sent me home.

So there I go, back with the kids at home, scheduled to have some injections of iron in my butt and another test in a week. When they tested me again my hemoglobin was down to 56.

Yes I was slowly dying, so they finally hospitalized me until my rare blood arrived from Québec. After a blood transfusion my levels went up to 76 and they sent me home. The diagnosis at the time, after many tests, was NOTHING. At one time one of the specialists tried to convince me that my monthly period was the problem, and wanted me to have some procedure he recommended. I refused, because in my heart I knew that was not the problem.

So, there we go again, test after test after test, being prescribed iron and having my blood level checked (which was going up and down). I remember during that struggle telling my friend, "I think I can face anything but not cancer." At the time, cancer for me equalled death! I remember one time sitting in front of a specialist asking him, "Are you sure it's not cancer?" — he said it wasn't.

I went back to work full time after my maternity leave. None of the tests were conclusive, and my iron and blood levels were acceptable. But there was one last test to do — after so many — that my doctor recommended. Tired and fed up, I accepted. And there, we finally saw a mass. They told me we needed to do a laparoscopy as soon as possible to take that out. I asked him if it could wait because I was replacing everyone at work and it would be better in September when everyone got back to work.

And there we go, a 2 hour surgery turned into 5 hours, with 8 blood transfusions. There were about 10 people around me when I woke up on morphine (life was beautiful, ha ha). Some were crying, some were panicking — they never saw that THING before. After a couple days, the VERDICT, GIST. What the hell is that, I questioned, they said it's cancer. And there I go crying thinking "this is it," crying because I can't imagine my kids without me, they are my life! Special friends all came to see me at the hospital and I will never forget them, we laughed and cried.

They then announced that I was going to take Gleevec, just approved a few years ago by Health Canada (I had to fight with my insurance to get this medication of over \$3,000 per month approved). So I took sick leave from work because the journey of the unknown began. At home, I cried for one night and that was it, I was going to win this battle and that's it. When my seven year old son, asked me if I could die, I told him yes. I saw his little crying lip curling, and told him, "You know what my love, the doctor told me yes I could



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die but he also told me I could live until 90 years old and that is what I've chosen." He then asked me if I could stay until 103 years old, I said OK, and that was the deal.

After two years of being more fragile because of the unknown, but strong as hell at the same time, I went back to work. Since 2006, I've had 7 surgeries, so many CT scans that I stopped counting, about 7 pet scans, x-rays, and so on. They took out part of my small intestine, half my thyroid gland, my ovaries, my uterus ...

there are so many cuts on my belly that I have been blessed with a cross on my belly. I was told that it was a miracle after the second surgery because they found nothing, contrary to what the test indicated. Before each surgery I always felt afraid that I might not wake up — my kids, my kids! Those surgeries became part of my life, so kind of a "no stressor" for me. After every surgery I got back up, went back to work, and gave 100% and more. Perfection is in my blood, I needed to be perfect as a mom, as an employee, as a friend ... tried to be a good partner, a good daughter.... But we all know that perfection only exists in our minds and can be a hassle too!

Unfortunately, or fortunately, GIST came back in 2015. During my 7th surgery they found little nodules, and took them all out (so they said). I needed to take a serious step back this time, but I still got back to work. "Why in hell," I'm thinking, "did they decide to keep me at 400mg?" Obviously that drug dose was not doing the job. I pushed and pushed, as usual, with my non-stop questions, always needing to understand (my life, my body). I went to Montréal twice for a second opinion, pet scan again, was working full time, taking care of my two, now adolescent, sons — OH MY GOD! I got about half an hour with that specialist in Montréal (3 days travel, as I live in NB), in all respect to him, he did not have time to talk to me. After seeing my pet scan, he said the Gleevec dose should be doubled to 800mg.

As I was trying to work through that, taking care of the family and everything else, it became just too much. So I stopped working until I could adjust to this new life with 800mg. Jogging my way through all this, yes jogging almost every day, I started coughing, my chest was hurting, and I was out of breath a lot. So, I told my doctor that I must have water on my lungs or my heart. After tests, oh yes I did have water around my heart, and they took 800 ml of water out of my lungs. The specialist in Montréal came to the conclusion that it was not because of the Gleevec, and I needed to get back to 800 mg, so I did. But I went for another opinion with the oncologist in my province and he told me he thought this water thing was because of Gleevec (2 geniuses telling me two different things). So, he said they would keep a close eye on me, check my heart & lungs, and do a pet scan every 6 months. He

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told me I should try 600 mg, but I remember that the specialist in Montréal told me that, no way can I go back to 400 mg, 800mg it is — so WHAT DO I DO!

During this process, only a couple of months ago, I decided to try 600 mg in order to try to have some type of quality of life, and get back to work. The last pet scan indicated that the GIST IS under control for now. The future is a mystery, my next pet scan is in May.

I can really say that my biggest supporter was myself, my way of thinking, my good way of eating and staying active. It's been hard for others around me because I want no pity. In my mind anything is possible and no doctors will tell me when my life will end.

I am slowly learning to try to expect less from myself, in a way, except for my health which must stay my priority. I can say that GIST left me feeling alone in the fight. I couldn't discuss it with anyone because no-one understood. Besides being tired, and having puffy eyes and side effects, no-one can see my illness, and I still have my hair on my head, thank God. I

often feel like people really don't know what I'm going through. But I have special friends who have been there when they could, kids that challenge me every day but that I love to death, and a partner that does his goddamn best to endure and help me the best way he can.

I'm tired, but back to work ... always there for my kids even if they don't always see it and appreciate it, so I think. I'm living with the unknown and challenges every day, but surely not afraid and will

live! Whatever it takes I'll keep going on! **Stronger than ever!**

If you ask me if the word cancer scares me now, hell no! If you ask me if I get tired and feel like my brain is going to blow up with this crazy life and get discouraged sometimes, hell yes! But it never lasts long, I don't have time for that!

GIST DOES NOT DEFINE ME!

Sophie

P.S. Thanks to all my supporters: Simon, Maxime & Alexis xoxo; mom & dad; family & specials friends / colleagues (you know who you are, I'll never forget!); and all the great doctors in my journey.

Special thanks to my family doctor and her secretary who have been there almost every other week in the last months!

