My worst nightmare as a SMC was losing my job (which happened), but what we are going through is worse. Since I can remember I have always waved off most of life’s difficulties saying, "This is not a problem. A child with cancer, now, that would be a real problem." When I first heard the bad news from our doctor, one week after celebrating my twins’ 6th birthday, I was so devastated that I wanted to disappear. I don’t mean suicide, I am well aware that I am fully responsible for the two children I brought to life, I mean that I wanted to curl up into a cocoon and vanish, so I would not have to see my child go through all that was coming. People kept saying, "Be strong," and I thought that was ridiculous. I chose to be a SMC and gave birth to twin boys at age 33, got a PhD, lost a job and a career and built it up again, lost my house in the process and have always found the way to keep on going. I have been strong my entire life but I could not be strong for this. No one could!

My son’s biopsy surgery was halted because the swollen node on his neck had spread all over his chest, his trachea, his heart and pretty much through every lymph node in his body. The anesthesiologist was concerned because he had a metabolic disorder so he could not have lipid-based anesthesia and the chest mass made it dangerous for her to use general anesthesia because his lungs could collapse. To use her own words, “a simple biopsy could be catastrophic,” for my son.

Not for the first time I wished I had more information about my twins’ genes. The biopsy was finally performed under a strange type of anesthesia that causes hallucinations. Then the Oncologist called me and my family to a private room. I knew.

“Precursor T-cell Lymphoma/Leukemia,” and it was all over his little body, including his blood and bone marrow.

After the initial shock some of my first concerns were, "Is his twin at risk?" and "Will my son ever get to meet his genetic dad?"

My son Ricky had been asking to meet his genetic dad since he was three. At that point I had two reasons for contacting CCB. In addition to providing more information to my child, I also wanted to know if there were cases of metabolic conditions or autism in his family, since there were none in mine. I found out about my sons’ metabolic condition because by age 2yrs it was obvious they had speech delay. One therapist recommended me to a doctor, a doctor to another specialist and so on, and all those times I had to repeat over and over, “I don’t know half of my children’s health history, but I will try to find out more.”

I contacted CCB and they were adamant about not contacting the donor or providing me with information about him, going as far as saying that they discouraged contact among donor families and refusing to recommend the Donor Sibling Registry (DSR) to a donor because there was no way to prove that the donor was whom he claimed to be, and their anonymity had to be protected as promised above all things until the child turned 18. It made me feel as if I was seeking something forbidden, sinful and illegal, which I know very well is not the case. My children have an innate right to learn about their origins. Even if they are under 18 they feel a connection to this stranger and so do I. So I continued to argue my point with the CCB representative, until my insistence let him to transfer me to a genetic specialist. Initially the genetic specialist tried to be nice, but as our conversation kept going in circles my A-type temper escalated. Eventually it became time for both to give in and meet each other half way. I accepted that I could not contact the donor and they agreed that they could contact him themselves, to inquire further about his health and bring him in for more testing. So I let them contact him and I waited for a response. And I waited. I spoke and emailed the genetic specialist again a few days later, then a few weeks later, then every few months. I knew it could take some time, that the ball was now on the donor’s court, and that I had to accept his choice, that he might not be ready, but I had no idea how long it could take. The genetic specialist at CCB kept saying the donor had not contacted them back.

When my boys were 3yrs old a speech therapist and an ENT recommended they get ear tubes. That was their first surgery, the first time an anesthesiologist needed genetic information to choose the correct anesthesia. My educational background includes enough Physiology and medicine that I know the dangers related to anesthesia, and some of those dangers are very much genetic. I emailed CCB with more urgency, but obtained the same reply, “the donor has not contacted us.”

By the time my boys were 6 yrs old I had stopped contacting CCB on a regular basis. I had probably contacted them months or even a year before my son was diagnosed with cancer.

I have been in touch with a group of about 12 families of siblings (a total of 21 children) since my boys were 1yr old. On facebook we exchange pictures, health information and watch the children as they grow. The children meet through Skype and the families that live close by meet in person. We are an extended family. I kept them in touch of Ricky’s condition as it progressed, from the time I thought it was a simple throat infection to the moment his biopsy results came back. They were devastated, as if it had happened to their child, as if their children had the same probability of having the same diagnosis as mine. I once again contacted CCB, this time in tears.

*One of my twins was diagnosed with cancer yesterday.  I wanted to report this as part of the medical conditions and ask that now more than ever please, look to contact the donor.  I would like him to know that my boys exist, that they are wonderful and beautiful and to give him the chance of getting to know them NOW.*

*I know he was probably a student and has now moved and the only email in record might be his student email.  Please, do EVERYTHING in your power to contact him.*

*We are in the hospital right now and will be for at least four weeks, but as soon as I can get to a printer or pen and paper, I will send that letter to the person you mentioned before.  What I ask meanwhile is to get an accurate contact information from him.  I want to give both my son and the donor a chance at knowing about each other.*

*We are still dealing with the metabolic disorder and speech delay (educational autism for one of my boys) but none of those things were life threatening.  This new condition is.*

*Please, do everything in your power to make sure he is contacted, in person.*

Their response was that the donor could only be contacted by the child when he turned 18, and that he would be informed about the medical condition during his next routine update.

Frustrated, sad, and overwhelmed with the demands of my son’s new condition, I stopped inquiring.