

Statutory Declaration

I, Atchynia Ruby, P.O. box 524, Whapmagoostui, J0M 1G0, 1977-09-28

(Name, first name, address, birth date)

I do solemnly declare that,

I will talk about what I went through with Patients Services in Montreal. My son at that time was thirteen and on March 1st 2012, he was diagnosed with leukemia. Here, he kept complaining of pain and we kept taking him back to the hospital. His pain was travelling all over his body, but the nurses and the doctors kept telling us that it was a hockey injury, because he was playing hockey at that time. They sent him home with Motrin and Tylenol. It came to a point where he couldn't use his hands, so I said that something was really wrong. I took him back to the clinic and demanded that they sent him out for evaluation instead of sending him home with Motrin and Tylenol. They finally sent him to Val-d'Or and I went with him. They did the tests, and on the 2nd or 3rd days that we were there they told us that they would send him to Children's Hospital in Montreal, and that he would be on a plane but that I couldn't go with him. At that time, we didn't know what was going on, they didn't tell us anything, they just told us he was going to get transferred and that I couldn't get on the plane with him so I took the midnight bus from Val-d'Or to Montreal to meet him there in the morning. I had to leave him at the hospital and he was scared.

I went on the bus and I was already there at the hospital, at the emergency entrance, when they brought him in finally. He went through more tests and that evening they told me that he had leukemia, the cancer that they found in his blood system. I was alone, and only the doctor came with the social worker that gave me the news, so I had to break the news to him on my own. I don't remember much for the next couple of days but they told me that there would be radiation. They didn't know if it was the terminal one or the one that could be cured. For the next two-three days I don't remember what happened.

I asked for an escort from Patients' Services, for my husband to come down and be the second escort. They said no, that a patient was allowed only one escort. For two-three weeks I was there alone with him because they refused to pay for a second escort. Finally, I said that I hadn't made that baby on my own, it takes two to make a baby; I had a really bad time coping alone and I couldn't cry or show my emotions to my son. When he found out he had cancer, the first thing he said was: "So I'm going to die?", so I had to tell him not to give up. And all this time I was alone. A ticket out of here is like \$2000 and we didn't have that money to pay, so for two or three weeks I was alone, still asking them

Declarer signature _____

Declared before me, _____

at _____ on _____

for an escort to help me, staying in the hospital, and they kept saying that it was in their policies for one patient to have one escort. They had the file saying that he was diagnosed with leukemia.

Finally, I don't know what changed but they said that finally they were going to pay for a second escort. My husband came down with my mom and my—I had two young kids at home, at that time I had a toddler too. We stayed at the hospital for a month because he had to go through radiation. They had to transport him from the Children's to Montreal. I went on the ambulance with him because he had to be isolated.

When it came to the point where he could be an outpatient, the doctors told me that he had to be in a very clean place. It had to be completely clean, and they told me even myself I had to have good hygiene around him, and for him too. At that time he couldn't bathe himself, so I had to bathe him, because his hands' joints hurt so much that he couldn't move them. They put us at the Hotel Express where they kept patients at that time. The cleaning ladies only came every second day to clean the room, even though the Patients' Services were told they had to clean it every day, completely disinfect every day. The washroom, the linen had to be changed every day, but they still only came every two days. And the food there is not really what you call healthy food, there were times when it tasted like it was just reheated from the night before. Like it was dry rice where it was crunchy, it wasn't prepared that day and the menu was, it was like they used the same seasoning for the chicken, the rice, the meat. My son didn't want to eat there, he lost his appetite. He was a picky eater because he was used to traditional food too. Even if they cooked fish there, they still put the same seasoning as the drumsticks. I had to go and pay for his meal, I had to walk around in Montreal to find what he eats and pay with my own money. They were saying that we stayed at the Hotel so we were not allowed to have money that was given to other patients that were staying in private homes, but he didn't want to eat that, he couldn't eat that, but they said that I had to use my coupons and had no money. I'd gotten to a point where I had no income, because I had just started my job and I didn't have the benefits where they can pay me to take care of my son. I didn't have holidays or anything. It was just my husband working, but at the same time he had to take care of our kids here at the house.

I kept calling them, they had to put us in a private place. They said they couldn't put me anywhere else. I found out by accident that there was a worker there who had a daughter who was a patient and that needed special care too, and she was staying at the Marriott Residence Inn, and it was being paid by CPS, but they were telling me they couldn't put me in my hotel's preference; they did it for a person that was working with them. I bumped into her, that's how I found out. She told me they were giving her money every week; she was a long-term patient with a little boy too. I asked for this because I know there is a kitchenette. That's how I found out and I told them they had a patient, and asked why they were telling me I couldn't be there. I told them they weren't following what the doctor said that it had to be cleaned every day. I finally told my social worker, I forgot her name, she was assigned to me by the Children's Hospital. I finally told her everything, and she said she would call a meeting and would be there with me to ask them for what he needs for his care. They were making it sound like I was demanding that for myself. They made me feel like it's in their policy and all that but they were letting other people break the policy.

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We had a meeting with them, the social worker came as a witness and my spoke person. Everything I asked them, to be in another motel and the meal money, they had no hesitation—not the way they treated me for the past month about getting what he needed. Every time I asked for what is required for him, they were saying yes, just because the social worker was there. They weren't fighting me. The social worker at that time was [REDACTED] from the CPS and the liaison nurse for Whapmagoostui was [REDACTED]. I don't know if they still work there, that was like five years ago. Anyways they said: "Okay, you're going to move in there", so we had the meeting in the morning and in the afternoon they moved me to the hotel that they had said no to me. The same day they moved me. The social worker gave them a paper and said it was what was needed for him, so that he wouldn't get any infections. So every day when I was there the ladies told me that my son could stay but I had to go, the motel sent three ladies to make a fast clean-up, disinfecting in each room. I would tell them it was clean, that we needed only the bed, but they said it was their work and they had to disinfect everything. Every day they came, and sometimes they would check if I needed another cleaning in the evening.

We stayed there from April until October. In September, when he had a bone marrow transplant, he was in the hospital for four weeks, and he was in isolation so I went back and forth with him. My mom was there with my kids too, my toddler because I left for a long time. In September I did some research and I said that it would be cheaper for them if I looked for an apartment fully furnished with all the utilities included. We found a place which was not far from the hospital; it was close to \$2000 a month to be living there with everything included, completely furnished. I told them in September, I called CPS and said I was looking for an apartment that would save costs. They said they didn't rent apartments and I asked why. They said they just didn't do it, it wasn't in their policy. I told them they were paying almost \$5000 a month for the hotel, and that I had found a place for \$2000 a month, and I wouldn't need transportation, and they still said no. They were willing to pay \$5000 for us to stay there. I hung up on them because I was constantly mentally fighting with them, so they called back and said they would move me to the apartment. I told them the doctor didn't know if we would stay for six, twelve months or even two years, and I was just trying to cut the cost for them. They finally agreed to it and when we moved to the apartment, I was never checked up on. No social worker, they would tell me the appointments but they would not come and check if we were okay, how we were doing. There was no follow-up with them.

Q1: Were you always in contact with the same person?

A1: Yes. It was always [REDACTED] for that duration, for the year.

Q2: It was always [REDACTED] that decided not to go your way?

A2: Yes, but she always used to say that she'd talk with her supervisor. I think at that time she was new to the organization, so she always told me she asks the supervisor, or the nurse, or whoever.

Q3: Do you know [REDACTED]'s last name?

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A3: It was [REDACTED] that was our case worker.

Q4: I thought she was the social worker at the Children's?

A4: No, I can't remember the social worker at the Children's but I still have the book, I can give you the name after, she's on the contact list. [REDACTED] is the CPS, and [REDACTED] was the CPS too.

Q5: But she was a nurse?

A5: Yes, the liaison nurse for Whapmagoostui. Anyways, after he was finished, and then we were told, I think we came back in April but he still had follow-ups, every three months I think. A few months after we came back, I noticed a rash. In the hospital they prep you for everything, what to look for, how to monitor him, to check his vital signs, and they trained me to give him a needle for his steroids. I noticed a rash on his neck, so I took him to the clinic here and I told them I believed it was shingles. I was told it was just a rash that it was from the water, or from a soap, or an allergic reaction to food. I said it was shingles, that I knew how to look at it, and they just kept giving him steroid cream and change the cream. He was in pain, so finally I said no. I called his doctor at Children's and I told them a rash had been there for four days and was painful. The doctor had to call and ask the doctor here to put him on a plane right away. They knew he had to be monitored here that every little thing they had to go to have it checked out because he was in a fragile state.

We went on the plane that evening, and when we got there the doctor said I was right, it was shingles that he had, and that they shouldn't have played around with that, it could have been fatal. He asked me what kind of doctors and nurses we had up there. He said I was very lucky it didn't kill him. From then on I didn't call here when there was something wrong with him, I called the doctor on call at Children's and asked him questions. Dr. [REDACTED], his name is Doctor [REDACTED] that was his doctor. I can't remember his first name.

Ever since them, we didn't go through them; it's hard going through that because you don't know if it's the last time you'll see your son because he is battling cancer. We had a really hard time mentally with them, it's like they were blocking us. We had no support from them, mentally or emotionally. It was a lack of support, they did what they had to do to give us a place to stay and I'm grateful, but other than that there was no support from them. That's Cree Patients Services.

After the shingles incident, the doctor told us, Dr. [REDACTED] to call Children's directly. So from that time we called directly over there when something was wrong with him, and he would make the request here if there was something to do for, like fever or anything like that. He said that for every fever he got, to bring him; he has to be assessed. But here, they said to take Tylenol or Motrin. They didn't even bother wanting to see him or anything. They said it hadn't been three to five days. I said he was

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Déclarant

fragile and that as soon as he gets fever he needs to be assessed because of what he is battling. That was with them locally here. I think that's about it.

I really wanted, for the future, if a child or a minor go through anything, that it has to be both parents, not just one, for emotional support. That two escorts can be paid for the child. With something severe like that, it has to be automatically two escorts, either the other parent or somebody else. I really had a hard time being there alone for three weeks, not knowing.

Q7: You came to Montreal three weeks later?

A7: (Husband) Yes.

Q8: What made them change their mind?

A8: I think they were tired of me calling every day and pushing really hard.

Q9: What is your son's name and date of birth?

A9: [REDACTED] November 13, 1998.

Q10: Do you think that the whole situation would have been managed differently if the family and your son weren't Natives?

A10: Yes. I think it would have been managed—I have a friend that her son was diagnosed with that rare disease Kawasaki, and she was sent out right away. She went to the clinic and the next day he was sent down for an assessment. But here, it took us two weeks to finally get him out to be assessed.

The other thing is that locally here, when you call after hours for medical attention for someone, the first question they ask you is if the person's drunk or on drugs. That's the very first question they ask, which is unprofessional, they are stereotyping. I don't think that if you call in Montreal and explain a situation to an emergency worker, I don't think they'll ask you if the person is drunk or on drugs. Here it seems it's the first question they ask all the time when they pick up the phone and you need medical attention from them.

I had an incident with my teenage daughter a few months ago. She saw the child's psychologist here, she is a case with social services here. She was going through a teenager's depression and she had problems with her boyfriend. We suspected that she had been taking pills, she had iron pills and we thought she took them. We called the clinic and said we wanted them to find out if she had really taken them, or if she was just tired. I saw an empty bottle of pills. The nurse on call, his name was [REDACTED] he

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Enquêteur

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Déclarant

first thing he asked me was if she was drunk or on drugs. I said I didn't know but that I thought she had taken pills so she must be drugged. He said to bring her, he'd be there in ten minutes. At that time my husband wasn't in town and I had my toddler with me, I couldn't leave, so I asked her older sister and her boyfriend to go with her and they went. After an hour to an hour and a half, my daughter that was supposed to be assessed came in running and she was hysterical, crying and getting mad. I held her, she wouldn't tell me what was wrong. A few minutes later my daughter came in with her boyfriend and they were mad too; I asked what was going on. They said they were trying to change her mood and cheer her up, and she was actually laughing in the medical office; they were trying to lift up her spirit. The nurse walked in and asked why she was laughing, saying that she wasn't supposed to be happy and laughing. That completely put her emotions down and she started crying again. I called the nurse on call and I asked why he had said that, that he must be trained professionally not to do that. When a person is going through that, if you see them happy, you're supposed to say that it's nice to see her smiling. His answer was that he was tired and they must've misunderstood. I hung up on him and the police came. They told me that the nurse had called and asked my daughter to be taken in custody and to bring her back to the clinic because he needed to finish his assessment. I believe it's because he won't be paid until he finishes his assessment. To bring her handcuffed, to bring her back to the clinic, that was the request from the nurse that was assessing her. So when the police came, I explained the situation to him. He agreed with me and said he wasn't supposed to do that, and he said he wouldn't take my daughter if she was okay, because he didn't like the nurse treated her. We never got a call back from the nursing staff either.

The other one was last spring with my father. They were at camp, he was sixty-eight at that time, and he has a heart problem, his heart is only 35%. I was working in town and they had called the day before, and they said to let him rest. Then that morning they called and said he was worst, and in the afternoon they said he was worst. In the evening the dispatcher called me and said that my brother had said he had never seen my father this bad, and that he thought he needed to be picked up. I called the nurse on call and she didn't want to send the plane; they were about sixty miles south from here. It was 7:20 am in the evening. The dispatcher said that they kept asking the same questions as in the bush kit manual. It was the same questions over and over and they just said to rest. Every time she called there, it was the same questions. She sounded worried too, the radio dispatcher who made the bush calls.

I went to the head nurse, knocked on her door and I said that I suggested that she sent a plane right away, that my father wasn't feeling well and that she knew his file. I told her the nurse on call didn't want to send it. She ran over to where the nurse on call was, she called Air Inuit and within twenty minutes the plane left. This could have been avoided, she should've sent it in the morning. If I would've gotten here ten minutes later, after 7:30 am the plane couldn't have left. After 7:30 am they don't take any more calls, especially in the bush where there is no light. They sent a plane there, he came back, and it was the first time I saw him in that state in my life: pale, it was like he couldn't recognize me, his heart was 156 per minute. The head nurse took me out of the observation room where he was, and she said it was a good thing I had pushed for the plane because they didn't know what could've

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Enquêteur

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Déclarant

happened during the night in that state without medical attention. The next day they sent him out in Montreal for more assessment; it's when they put the pacemaker.

It's stuff like this, they are barely getting off with fatal decisions like that. I don't know if they are lazy, I seriously can't comprehend how their mind is, especially someone who is trained to assess or help people medically, I don't know how they think.

I really don't want any persons to go through what we went through with our son. Not the emotional fighting, there was hardly any support from them. They were just blocking us, everything we asked, it was one block after another. So that's our story.

Q11: All the events happened during a short period?

A11: Within five years.

Q12: The situation regarding your daughter, it's not clear to me when it happened?

A12: January 2018. With my dad it was the first week of May, last year, 2017. First or second week of May; I'm sure they have all the records there.

Q13: What is your daughter's name and date of birth?

A13: [REDACTED], April 8th.

Q14: And your father?

A14: February 23, 1949.

Q15: And his name?

A15: [REDACTED] That's another thing, he's a very special case with his heart problems. Once, I had to force—he had sweating and palpitations, two years ago, I had to force the guy to see him. It's like they don't relay to new workers, the new nurses, it's like they don't relay about the special cases. I had to really force that guy to see him, to monitor his heart. I don't know what kind of training they get when they come in, or the orientation they give them when there are new nurses here, because I really had to fight. I was on the phone with him for five-ten minutes, saying he had to see him and that he had a heart problem. Then he took him and, of course, the monitor was going crazy; he took me out of the room and thanked me for pushing, saying he didn't know of his case. They don't give them orientation for the special cases.

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Enquêteur

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Déclarant

Q16: It could be a good recommendation for the people that come.

A16: Yes, the new ones, to actually give them orientation on the cases. That guy said he had been there for a week or two, and he thanked me for pushing because he didn't know his case. They should do that here, or anywhere in the communities. It's quite a big battle for me and I'm very outspoken.

Q17: Do you have any other suggestions to improve those services in the future?

A17: I believe that Patients Services should be going to the patients, and not the patients to the Patients' Services. Follow-up on them, see if everything is okay, see if they are comfortable, if they are getting the proper care from the hospital they are putting so much money for the care. That should be there, the communication, and I believe they should get their own communication officers, especially in Val-d'Or and Montreal where the big clientele is. The patient's escort could take their concerns and suggestions. They should have someone right there that can make suggestions at their board meetings. They should get someone like that, someone you can go to talk about the treatments received in the hospitals. Nobody ever looks at it that way.

Q18: In Val-d'Or, how was the communication with the professionals?

A18: There was hardly any. They didn't even tell me they found out that my son had leukemia. They just sent me to Montreal and it was in Montreal that they told me. The doctor there thought I knew he had cancer, she was surprised I didn't know because they knew in Val-d'Or. They didn't tell me, all they told me was that he was being transferred to Montreal. I thought he was being transferred for further assessment. I don't remember the doctor, we were there two nights and it was different doctors that came in. I remember it was an [REDACTED] doctor who came and said he was being transferred in Montreal. They knew at that time but didn't tell me.

Q19: Were they able to communicate with you in English?

A19: He was, he spoke good English, but I had a hard time with the nurses. I know a little bit of French so I could catch a word and I knew what they were talking about, but I don't think he would understand what they were talking about. For someone who didn't learn French at all, it would be too hard.

Q20: Was there an interpreter service?

A20: I don't know if there is, because usually it's the escort that goes to the appointment. Some words in the medical language are hard to translate to your patient; what they are actually talking about. They should hire interpreters that know the medical terms that they could translate into Cree to make them understand. They should hire them to be there with the escorts. I know some escorts who go and know a little bit about English. We have a hard time finding escorts here, they have to go outside

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Enquêteur

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Déclarant

their families to find an escort. Some people try to explain the situation but they can't find the right words. I think they need to hire people to interpret, and train them on medical terms, how to translate them in Cree, especially for the elders.

In Montreal they ask you if you know where you are going, if you need help, but in Val-d'Or they don't. I guess they figure it's a small place, but for someone who doesn't go there often, you sent them to a blood test and they don't know where to go.

Q21: So in Montreal there is an interpreter in Cree?

A21: Yes. They ask you if you need help or if you need someone to translate for you. It's fine for me because I understand, but for someone who didn't do much schooling, they are going to have a hard time understanding what the doctor is explaining to them and for them to explain to (the patient).

Q22: Through all those events, have you ever made a complaint?

A22: Not officially. I wanted the dust to settle and make sure my son was okay. Now is the time to bring this up. The three weeks I was there, the only communication I had was with my family through my cell phone. Nobody at the CPS came to see if we were okay. I had one visitor during the whole time, she brought me coupons for the cafeteria.

Q23: There is an office in Montreal, for CPS?

A23: Yes, at the Hotel Expresso. Hopefully they will improve their services. I think that's it for now.

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