

## Statutory Declaration

I, Berthe, Elena

(Name, first name, address, birth date)

I do solemnly declare that,

Q1: I will let you speak about the health issues.

A1: My main concern is about what I've experienced. I had a mother who had cancer and the fact that when they are in chemotherapy, I noticed afterward that we were never told about what to expect or what not to do or what to do.

I've had other families down south that are non-native, as I am both native and non-native, and when my aunt had cancer, I noticed that we had to be very careful. When we visited her in her home, we had to sanitize and she had a very good information about what to eat and what not to eat, like raw, and if people had health issues, such as colds and so on, they were not to go near her. When she's on chemo, the hormones cannot fight these bacteria. That really hurt me and I felt that we were never told during my mothers' chemotherapy for 2 years.

Q2: Where?

A2: She was home and was flown out to Montreal and she would come back.

Q3: When she was flown back, was she accompanied by an escort?

A3: Yes, they did.

Q4: Did anyone in Montreal inform you about those precautions?

A4: No. no one.

Q5: Just your aunt, because she stays in the south?

A5: I only found out all these procedures because my aunt, after years later that my mother passed away, was going through chemotherapy. I felt bad and we were never told these, because had we known, we would have made sure. I took care of my mom, I gave her meds, but we were not informed about these precautions. We would always give her raw food because that's what she wanted and not knowing that they should not be doing that during their chemo. The fact that we are Inuit, we shake hands, we welcome everyone in the house, but sure if I had known I would have had a hand sanitizer, ensure that anyone with colds would not go near my mother. After she had her chemo, for sure, a lot of people would visit because that is our way of welcoming people. She died of pneumonia because I know she caught it from someone.

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Declared before me, \_\_\_\_\_

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Because we are Inuit, we are” *not being told or whatever*” that’s how we felt for a long time. I was so angry for a long time.

Q6: Who were you angry towards?

A6: The system. I felt not important as an Inuit, and now I ask patients that are going through chemo, not all of them because I know some of them are told, but it’s still an issue. A lot of them are not being informed about these situations.

Q7: So, not once when your mother went to Montreal, did the doctor tell you?

A7: No, I escorted her a few times and never once were we told. All we were told was once we found that she had only 6 months to live but she lived for 2 years because she fought.

Q8: Who do you think is responsible for informing?

A8: Health system, I think.

Q9: Here, and Montreal or wherever?

A9: Yes. I think a lot of them think that we know automatically about all the information and chemo. But they are a not all knew to a lot of people. A lot of us are not educated that well and the health system also... So, we don’t know right away. I’m not blaming anyone, but I am still very concerned and felt that we should be informed.

Q10: What year did your mother have cancer?

A10: In 1999 or 2000 was when they found out.

Q11: And she passed 2 years later?

A11: Yes.

Q12: Then, your aunt also had cancer?

A12: My aunt also had a cancer, 8 years ago. She is Qallunaat, she’s non-native.

Q13: So, that’s why you felt that, because she’s non-native that you knew now what a cancer patient needs?

A13: Yes, because I had to visit her at her place and I had to do all this. So, I started asking questions: “when I found out I had cancer, I met with the nutritionist...” all that, everything. I was surprised because we had nothing.

Q14: So that’s why you felt discrimination?

A14: Yes, very much.

Q15: Do you think it has changed since today, or has it remained the same?

A15: That’s my concern, that cancer patients should be very well informed, if it’s still not happening. But with the nurses that we have now, I’m not sure if they are telling the patients because once we have a nurse that stays for a long time, they start to really care, like they do care and they tell us.

Q16: To give the proper services?

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A16: Yes, I'm sure and I hope that it's happening, I can always ask because I usually have a good relationship with the health system, here in the community, but regionally it should be.

Q17: The professionalism should be the same up north.

A17: Yes.

Q18: Do you have something else to add about the health issues?

A18: No, not really, that was my main concern that I had to go through. I felt that I had to share.

Q19: What kind of recommendation would you provide so that this doesn't happen again?

A19: The recommendation is, for us, to have all the information we need, even though they think we know. For example, during chemotherapy, it's highly recommended that they be treated the way cancer patients are treated down south. Because, they have to fly down, return and even our houses that they are going to stay at, they should be well sanitized and ensure that they have the help. We don't often have that here for cancer patients, when they come back from chemo. The housing system, as there are some living in mouldy homes...

Not long ago, we had one patient that was living in a mouldy house, and it was unacceptable for her to be living there but thankfully she is cancer free now. It wasn't good for her. She had to fight so much, and we knew right away that she kept getting really sick because that house was not safe. There was no one to work on the house, it was too slow. They don't really take care of situations like that.

Q20: In that situation, what did you propose to change that?

A20: We tried to ask for her to get a house, to move to another house, but there is a lack of housing and we had no power on that.

Q21: So you need more than what the community can provide and you said that that it is also the responsibility of the government to do something about that?

A21: Yes.

Q22: Do they do that down south?

A22: I don't really know but I know they have more choices in housing.

Q23: And resources too.

A23: Yes and it's quicker for them to get the services or to have the house tested before it gets mouldy. We always have to fight to let the government, the housing, the system to get answers. We have to prove everything and sometimes, we just give up.

Q24: Because you get tired.

A24: Yes, we just get tired, especially with the turnovers and have to re-explain the situation to new workers. It's just a circle. So that's my main point.

Q25: Anything else?

A25: I do work with the elders. I voluntarily give lots of time for the community because there is a lot of lack of resources or education, or they don't understand. For example, when they receive

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retirement or pensions, or when they just need to make a telephone call to the government for their mail. I find it frustrating and I feel pity for the elders when I have to be their translator. The government doesn't understand that the elder doesn't understand English or French. We try to tell them that we are Inuit and that there are no services here and they tell us to speak English or French. Once, I was told, "*Tu restes au Québec, mais tu parles même pas en français.*" I tried to explain her that the person I am translating for doesn't speak French, he's Inuk. She started criticizing and I told her: "You're living in Quebec and you don't speak Inuktitut. Come on, speak Inuktitut. That's exactly what you are doing to us. I have the right to speak my language. You should be able to understand all the languages as you are working for us."

Q26: But you were there to translate?

A26: Yes.

Q27: She was mad because you were speaking English and you were there to provide the translation?

A27: Yes, and then, because we were speaking in Inuktitut too. I had to translate back to Inuktitut and then English.

Q28: Do you know which program you were calling for?

A28: CSST.

Q29: That was the kind of answer you received?

A29: Yes.

Q30: How did you feel when you received this kind of comment?

A30: I was even a sub at the daycare for 17 years. The doctor gave me a note for 6 weeks off because of stress, because I had a miscarriage during my work. I was still working even after my miscarriage because I was shovelling at 7 in the morning. I couldn't find anyone to go and shovel early in the morning so I would do it before the kids arrives. We have storms coming in every day and living in a small community, it's hard to find people.

So, after my miscarriage, I went into depression and the doctor gave me 6 weeks off and the CSST has to approve that it was stress leave. I was home had I got a call from CSST, and her attitude was "Bien là, c'est une garderie de trente places, comment ça se fait que tu es stressée?" over the phone how could you be stressed?"

Q31: How do you say it in English?

A31: "You are working in a 30 places daycare, how could you be stressed? Your request wasn't approved."

Q32: When did this occur?

A32: Around 5 years ago.

Q33: How did you interpret that?

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A33: It was hard. I was too shocked. I am a fighter, I could have done all that. But I said: "If you would come here and do what I do, you would know and you would understand how stressful it is. It is not just the kids I take care of. I take care of the whole building. Who are you to say that it's even not stressful?"

Q34: So you were taking care of the whole building. You were the manager?

A34: Everything. I am the Center Director and I'm on stress leave.

Q35: So she thought that working in a daycare of 30 places was nothing?

A35: Yes. But living in a small community, daycares are struggling. You have to go through a lot; we have to be the cook, staffing and ensure the safety of the children and the paperwork that we have to do. Especially with a small daycare like that, we don't have a receptionist, it is just us to be taking care of everything.

Q36: She clearly doesn't understand.

A36: No.

Q37: What happened after, did you receive money from CSST?

A37: No, because it wasn't approved. They didn't approve it.

Q38: Did they provide you with a reason as to why your claim wasn't approved?

A38: No, It was just not approved.

Q39: So I guess you were that tired, and that...

A39: Yes, I was just tired and the board ended up giving me time off instead of going through all that. I didn't have time and for the person that was saying that to me... I was tired and I didn't want to go and prove it. I know could have, I should have but I just didn't have the energy, because I was too much in a depression.

Q40: It's not a time to fight when you are in a depression.

A40: No.

Q41: Did you feel that it was disrespectful?

A41: Yes.

Q42: Did you feel that you were discriminated?

A42: Of course, if it was a non-native, they would have approved it right away, without any questions, like they do with the teachers. Stress leave right away and they get it.

Q43: Did she take the time to listen to you?

A43: Not really. I didn't want to have anything to do with her.

Q44: Are they CSST anymore?

A44: Yes.

Q45: How would you like that the government staff treat you?

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A45: To understand us. If they have questions, they shouldn't talk to us like that but with respect.

Q46: The fact that there is a language barrier is a problem here.

A46: Yes. So, that was my... I'm glad I mentioned that. But for the lack of services, for example we should have a code for our elders. They should have a translator without having to explain who we are. We should be able to use a code to identify first nations and that they instantly have a translator. It should be easy instead of having to explain everything to them. I have to always pretend that I am the daughter or ... even though they won't.

Q47: You propose that in the government departments, they should have someone who speaks Inuktitut?

A47: Yes and if not, they should have a code that identifies them that they need a translator, without having to explain everything.

Maybe in every community, that's what we are working on also, I proposed that kind of elders' coordinator that could be able to do that. To have a code at the government. Some kind of a system.

I just really have a heart and a lot of respect for the elders because, if it wasn't for them, we wouldn't be here. They fought so much and they survived. They shouldn't be suffering or having to explain all the time who they are and what they need. Finally, it's not fair so, each community needs to have a representative for the French and English speakers.

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