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4-24-2015

### Statement by Cheryl Lola and Mary Jenkins collected by Rachel George on April 24, 2015

Cheryl Lola

Mary Jenkins

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#### Recommended Citation

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## General Information

**Private or Public Statement?** - Private

**Statement Provider:** Cheryl Lola and Mary Jenkins

**Date:** April 24, 2015

**Location:** Motahkomikuk, Maine

**Previous Statement?** N/A

**Statement Gatherer:** Rachel George

**Support Person:** Stephanie Bailey

**Additional Individuals Present:** N/A

**Recording Format:** Audio

**Length of Recording:** 1:09:22

## Recording

**RG:** Okay. It is April 24, 2015. We're here at Motahkomikuk, Maine. My name is Rachel George and I'm here today with?

**CL:** Cheryl Lola.

**MJ:** Mary Jenkins.

**SB:** Stephanie Bailey.

**RG:** Excellent. And the file number is M-201504-00164. Cheryl, have you been informed, understood, and signed the consent form?

**CL:** Yes.

**RG:** Mary, have you been informed, understood, and signed the consent form?

**MJ:** Yes.



**RG:** I have to let each of you know that if at any point during this recording you indicate there is a child or an elder currently in need of protection or there is imminent risk of serious bodily harm or death to an identifiable person or group, including yourself, that that information may not be protected as confidential. Do you understand?

**CL:** Yes.

**MJ:** Yes.

**RG:** So I'm going to open it up to you both to start wherever you feel the most comfortable, talking about your experiences dealing with state child welfare and Tribal Child Welfare.

**CL:** Well, in the beginning when my son was first diagnosed with nephrogenic diabetes insipidus –

**MJ:** Grandson.

**CL:** – it was in – my grandson, sorry (*laughing*). Did I say son?

**SB:** Yeah.

**MJ:** Yeah. Your grandson.

**CL:** Grandson. Yeah, I consider him – but he was first diagnosed with nephrogenic it was in Eastern Maine Medical Center and uh—Dr. Woods was one of the doctors that were treating him and they couldn't understand what was going on with him because he was always thirsty and he was always using the bathroom, peeing a lot. You know, and he couldn't understand and when he said that to me, about the pee and the drinking a lot, that brought me back to his grandfather, Molihk's grandfather that what he was doing. Every time we went somewhere, like long trips like to Bangor or, you know, some place, he'd have to have me stop so he could use the bathroom and he always had some water with him. You know, he drank a lot of water. And then I told him about it so he researched it and he found out that it was nephrogenic diabetes, you know, insipidus that he has. So that started the whole thing going of he wanted to put Molihk in a home, in a group home so nurses can take care of him like a nursing home.

**SB:** The doctor did.

**CL:** Yeah, the doctor did.

**SB:** Okay. Sorry.



**CL:** So the nurses could take care of him because they didn't think that, okay, me and Mary we're not qualified or we're not – what is the word?

**MJ:** We're not equipped.

**CL:** Yeah. Equipped, yeah, to take care of him. We don't understand, you know, what he's going through so he wanted to put him in a home and I told him if he goes anywhere, he comes home with us. We're his family. We should be taking care of it. If there's something that we don't understand of what he does have, you know, put us – steer us in the right direction where we can research it like online and stuff and what he does have, you know. So that's what he started doing as soon as he was first diagnosed with it. You know, and then with the doctors at Eastern Maine, they called our – this child welfare, Tribal Child Welfare here, and that's when Diane Tomah got involved. When she started getting involved and she said well, we could put him in foster care, Beth Ripley; we could put him in her home. And I was like this is my grandson and it's her son, you know, why put him in a home, we want to take care of him, and we could learn, you know, of what he does have. And we know he can't have salt, you know. And so that's what – where the Tribal Child Welfare started in and they started coming around.

**MJ:** And they said, “Oh, think about it. “ They were just pushing us to put him into Beth's home and I didn't want him anywhere. I want him with me because I want him safe and I don't want, you know, anybody –

**CL:** Somebody else taking care of him.

**SB:** And they wanted to learn but they weren't – like, people weren't stepping up to teach her, really explain the severity. It's like the doctor said, this is a severe condition and they called child welfare right on them and said this child has high medical needs and so nobody was stepping in, the Tribal Child Welfare, to help give them the supports they needed to teach and learn.

**CL:** Help us learn, you know, what he has. And what did Joe, his grandfather – Molihk's grandfather kept telling me is that this is what he has, don't forget that word, nephrogenic because if you put diabetes insipidus, just that, it could mean like sugar, you know, diabetes or something like that. He said don't forget that word nephrogenic. So we didn't and every time we talked to somebody that's what we do, we do the whole what he has. And then we had a group meeting that was with Molly, Molly Newell. Alberta, my sister Alberta Newell, and the Tribal Child Welfare Diane Tomah, Anne Bergan, Dr. Woods was there and I think some nurses, you know, two that were there.

**MJ:** Me, you.

**CL:** Yeah, us. And they were saying, “Okay, this is what we see when he's been in the hospital so far and this is what he has,” and they -- did they say, you know, we don't feel that he could be adequately taken care of at home?

**MJ:** Yeah, he –

**CL:** Yeah.

**MJ:** Dr. Woods thinks that we can't take care of him. He said that we would kill him. That's what he said.

**SB:** Yeah, at one point they said unteachable is what he said; that come up in our meetings. And mind you there was no jeopardy order in place with the child welfare's engagement here. It was based on a doctor's call and then they're sitting them down.

**CL:** And then there was a woman coming in, what was her name? Ashley.

**MJ:** Oh, Ashley Look.

**CL:** She started coming. Yeah, she started coming in and we were wondering why all of a sudden these people, little by little, they all started coming. And then she said she was going to follow Mary and the family around a bit to see how they are and if they could take care of him, you know, and things like that since he's got high medical needs. And then we had that meeting, Ashley was there too, Ashley Look was there too and then – how long was he in the hospital?

**MJ:** He was in the hospital for two weeks.

**CL:** Yeah, two weeks he was in there and then when he came home then we – Diane Tomah and all them started coming around.

**MJ:** Yeah, they started coming and see how we were with him and stuff.

**CL:** So and then we kept having meetings with the Tribal Child Welfare while they kept coming around 'cause we didn't have meetings yet (*Inaudible*) because they didn't take him yet. They took him two months after. April, May, June, July.

**MJ:** Yeah, they took him September 15 of 2013.

**CL:** 2013, yeah. So that's when they took him into custody and they gave her a safety plan, they gave her a safety plan of what they needed to take care of.



**MJ:** Because Nancy came and then I was wondering why the state was coming.

**CL:** Nancy is the Public Health nurse.

**MJ:** And then when Nancy left the state came and the child welfare, Diane and Anne Bergen, and we sat down and then – because the state person was –

**CL:** Kim.

**MJ:** No.

**SB:** Shannon, no.

**MJ:** It's this blonde girl.

**SB:** Shannon --

**MJ:** I don't know, she opened the case.

**CL:** Okay, it wasn't Kim Tyler.

**MJ:** No. Kim Tyler took over.

**CL:** Yeah, okay.

**SB:** At first it was Tribal Child Welfare that removed him from the home, right?

**MJ:** Yeah.

**SB:** It wasn't the state.

**MJ:** No.

**SB:** So first it was the tribe that stepped in and removed him without a jeopardy order, and then the state got involved because the tribe didn't have the resources, is pretty much what they were saying, right?

**MJ:** Yeah.

**SB:** That the state could offer them resources and this and that when we were at the meeting. I remember them saying that and then that's when the state stepped in.



**CL:** And then when they took him, didn't they include Maya in that too?

**SB:** Well, yeah, the state – in order for the state to take him into custody, they had to – they are stricter about their rules and so they put a jeopardy order in and this – they were only dealing with the one – she has two children, an older daughter Maya and a younger Molihk, the boy with high medical needs. And they included Maya on the jeopardy order and she was never part of the discussion and they knew that Mary was an adequate parent for Maya and her and the father were able to provide and so that was a big shock, like what is this other child doing on this order?

**MJ:** But when the state came and that's when they told me that they have to take Molihk because I wasn't giving him his meds and I wasn't qualified to take care of him because his sodium levels were going up. And plus when we went to Oakland for his doctor's appointment, I forgot his formula and things that he needs and I only gave him water, so that's – I guess that's bad or something. And that's when they took him. If I didn't – if I didn't hand him over then they would call the cops to remove him so I had to give him up.

**CL:** That would've been a big –

**SB:** They wanted her to voluntarily to give him up, and they included – and they were in the meeting, they said if you don't then you will lose Maya too.

**MJ:** Yeah.

**CL:** So and then we went to court about that and everything and then – and before we went to court I think it was the first time (*Inaudible*). Before we went to court she had a meeting at DHS office in Calais with Kim Tyler, her lawyer John Churchill, and who else was there?

**MJ:** The –

**CL:** Guardian ad litem, John Hawks.

**MJ:** Guardian ad litem, me. I think that was it.

**CL:** Yeah. And then what happened there, I mean.

**MJ:** When I got there, I guess – I was a little late for the meeting, but I guess Kim Tyler told my lawyer, John Churchill that—to take me in the other room and give up custody to the state. I think that's what Kim Tyler told my lawyer. So when I got there I sat down for a little bit and then John Churchill took me in the other room and he was talking to me and he said, “Oh, you got to give up custody to the state.” And I was like, “No.” And he was like, you know, he was



like pressuring me, like if I didn't give up custody to the state then they would going to take Maya too so I had to.

**SB:** She felt up against a wall.

**MJ:** Yeah.

**CL:** So and I didn't think that a lawyer, your lawyer, I thought they'd be fighting for you, you know. I didn't think they could do that.

**SB:** And part of his reason, because I – they had called me in and said – ‘cause people know I do child advocacy work so they got my name from a relative of ours and they called me in and I started going to the meetings before the – Molihk was ever placed into – with a jeopardy order into custody, sitting in the meetings. I was very appalled at how these were being structured because there was no jeopardy order, like there wasn't anything, you know, other than we all knew that the child had medical needs. But they started calling in different people like asking Mary, what if we have this person come into your house and they can start teaching you so she was very open to all of that and Cheryl.

But the thing was, at one point these two had gotten into a quarrel, which families do fight, and so what they did was they were banking on that fight and trying to keep them separated. We were in a meeting and the nurse was – ‘cause Cheryl is very engaged, they help each other, they're a team, that's what we do, we work in an extended family and these are communities. And the woman in the meeting said, “Well, just because, you know, now that there's a love fest going on” – that's what she called it, a love fest, because they had made up from their quarreling -- and made it sound like it was a joke, like it was a fluke that them being back in good relations had nothing to do with the well being of the child, when in actuality it really does. It's a huge – their teamwork and their relationship is a big part of, you know, their family unit and keeping themselves healthy and together.

So every meeting we went to before the jeopardy order was put in by the state and they were being threatened with Maya, she was opening her door to all these different providers. She had like five different providers coming into her home, nurses and everybody, to come in to teach her and she was open and willing to learn anything. And so the foster parent who had her son, they didn't know that their relationship was well. She – Mary is very friendly, she's not confrontational and she just wanted to visit, so she was going to the foster parent's home to visit all the time. Well, the foster parent started making, you know, “The father isn't coming here, the father isn't visiting,” and making big deals out of it. You know, and then she would watch Mary and see her, what she thought was something wrong and instead of saying, “Mary, why don't you do this” or, “Mary, why don't you do that,” she would let Mary go and then right when we'd come to another meeting she would go and tell Diane and Anne Bergan that, “She's not doing the right thing, she's doing it wrong.” And so every time she was getting





close to maybe getting her son back, the foster mother was hindering the reunification process because she was tattle-taling at the last minute before the meetings, rather than being inclusive like we're a group, we're a team, let's work together so we can get what the child needs. And she was doing everything she needed to. So then to have the jeopardy order put in and threatened with Maya this was like way too much and her lawyer was no good.

**MJ:** He didn't do anything.

**CL:** And then the guardian ad litem came to see her, what, twice he came.

**MJ:** Yeah, twice.

**CL:** One time was as soon as Molihk was out of the home the guardian ad litem has to come in because he's the lawyer for the baby. And then he came in one day it was like, what, half an hour and just wrote down things of, you know, their information and things like that and then the second time was, I think, the next day he came like a couple seconds to see how Molihk was doing because he was just passing through town. And then he left and then they never seen him after that until we – what was it?

**SB:** Called him in.

**MJ:** Yeah, we called him.

**CL:** Yeah, we called him.

**SB:** Because I sat in the meeting in the house with you guys.

**CL:** Yeah, that's right. We called him in. I forgot why.

**SB:** The reason why we called – we wanted to meet with him was because we were trying to help him understand because he was – by reading his reports he was clearly against the family, even though – like, he wasn't recognizing how hard the mother and father was working to make sure they were meeting the demands of the child welfare and the state child welfare because they had both involvement from state and the Tribal Child Welfare. And so we wanted to sit with him so he could get some perspective, some depth into this side. Because he was spending a lot of time with the foster mother on the phone and visiting with the foster mother getting her perspective and her negative outlook of Mary and the father and Cheryl. Big negative here. The foster mother was fighting hard with the grandmother. And so we sat down with him to do that and he did sit with us for about an hour but he was very quiet and he just –

**CL:** Writing things down.



**SB:** Writing the whole time and then at the end of it he said, “Well, it seems to me there's a communication breakdown.” Because we wanted him to know, you know, “Why is Beth going and tattling on her rather than being part of a team, why aren't we a team?” And he said, “Well, it seems like there's a communication breakdown.” and he made it sound like it was on their side. He said –

**CL:** You need to start talking to Beth, you need to start being nice to Beth, you need to get along, start getting along with Beth. After our meeting he went over to Beth's house (*laughing*).

**SB:** And let Beth know what was going on. So he told her to behave and act right and be good to Beth and go over there and act nice and be kind and we were like, that's going on. That's happening. But when we get to a meeting we're blindsided by all of her information that shows how she's not capable of taking care of her child. I've never seen a hindrance from a foster parent more than I have in this case. This case lasted a year and a half. And in my opinion, my humble opinion being involved in other cases, it was the foster parent's involvement that hurt this reunification process. If this was a state case, 18 months it would've been done. But anyway, so we met with him, John Hawks, and then – so we did that.

**MJ:** And then when we –

**CL:** At that first court he talked to Sonya, Sonya Dana, because we invited her to court too. We invited her and then he was talking to Sonya and said I met with the mother, the father, you know the gram, you know, I just don't understand why this baby's out of the home, everything seems to be okay when I went over there to visit with them. And then when we went in to court he changed his tune because he was –

**RG:** So he was saying --

**CL:** -- talking to the state.

**RG:** He said that he didn't understand why --

**CL:** Yeah, he didn't understand.

**RG:** Wow. And then changed it when you guys went to court.

**MJ:** Yeah.

**CL:** And then changed it because I guess the state was talking to him, the Tribal Child Welfare was talking to him. I don't know what changed him. I don't know.



**SB:** And that Kim Tyler might've helped sway him. She – who was the caseworker, Kim Tyler was the caseworker of this case for the state DHHS, and she was always talking to Beth on the phone too. Like we got to read all of the logs because they send the logs to them so I would sit with them and we'd read their logs and understand what they were talking about. And so Kim Tyler was talking to the foster mother, Beth, a lot and Beth was, you know, always reporting the bad stuff to Kim Tyler and Kim Tyler was feeding that, she's a bad parent, the father's a bad parent, they're not engaged enough to our liking. Like they wanted the father, you need to come to the house and visit, you're not going to get this kid back until you start visiting. And, you know, I would be in the meeting and be like I've been in my family and I'm the mother and I'm the one that usually does everything and nobody better threaten my family just because my kid's father doesn't want to be involved, or my husband—like it was weird for me to see them so pushy on the father, Marquis' case, about him not wanting to go to the woman's house to visit.

**CL:** He told them in the beginning he wasn't going over there.

**SB:** And the foster mother was very inappropriate and always tattling and he hated it, so for him to go over there into somebody else's environment who he feels is backstabbing him was really hard, but DHHS and everybody that was one of their big heated – one of their things that they banked on. “He's not doing it, you're not getting him back.”

**CL:** And Diane Tomah, one of the logs said he told – she told the state hurry up and take custody of that baby already.

**MJ:** Yeah.

**CL:** And I was like, “What?” I read that on there, hurry up and take custody already.

**SB:** She told the state that, and she's the family advocate for the tribe. She said, “Are you going to stop messing around and take that baby into custody?”

**MJ:** Yeah.

**CL:** Yeah. We went through a lot with this.

**MJ:** And then Kim Tyler said, you know, had everything against me, like, you know –

**CL:** Everything negative.

**MJ:** -- the apartment's too hot or, you know, everything.



**CL:** And he's going to dehydrate and die. Like he's going to dehydrate and die right there in front of us like it's too hot in the house.

**SB:** Like they wouldn't do something to engage if they know – because they know his symptoms too. And the home – her home has radiant heating under the floor and so like when somebody in the whole building turns their heat up and down it takes a long time for that to come down because they're all apartments connected. So that – because they were supposed to reunify quicker and give her visitation. They were supposed to up her visitation, and every time we went to a meeting, because of the foster mother Beth saying something negative, they'd say, “No, we're not going to give you more time, no, we're not going to give you more time. Your apartment's too hot, we're not going to give you more time.”

**CL:** Or they'll give her some time, but they'll take it away.

**SB:** Take it right away.

**MJ:** Yeah.

**CL:** Because this is what happened.

**MJ:** Because it's, you know, there's something wrong.

**CL:** Yeah, there's something wrong.

**MJ:** And then when I got overnights, you know, I had –

**CL:** You didn't have those too long.

**MJ:** No, I didn't. Because a couple overnights they were doing good, but then out of the blue Beth was telling Kim that I didn't plug Molihk in right at a certain time.

**CL:** Yeah, because we were at my house and she was doing laundry over there. He was supposed to be plugged in at 8:00, Beth was sitting right by the elderly mail site—we could see the vehicle, Bruce's vehicle right there in the dark. They thought they were in the dark and we seen them when we were coming up the hill and I told Mary, did you see Bruce's vehicle up there. She said yeah. So we went over to her apartment after the clothes were done, it was like 9:00, he was supposed to be plugged in at 8:00, she plugged him in 9:00.

**MJ:** And then when I got into the apartment Beth called and she was like, “Oh, did you” – she was like, “Oh, you're home.” And I was like, “Yeah.” And she was like, “Oh, did you plug – what time did you plug Molihk in?” I was like, at “9:00.” She was like “Oh.” Like she has a big, she was like had an attitude about it. And then I asked Dr. Fremont (*phonetic*) because



when we went to that appointment in Oakland, I asked him is Molihk supposed to be plugged in at a certain time, and he was like no, as long as he gets that nutrition during the night.

**RG:** What do you mean plugged in?

**CL:** He has a –

**MJ:** A feeding tube.

**RG:** Oh, I see.

**CL:** Feeding tube.

**MJ:** So but he was like as long as he gets the nutrition during the night he should be fine. But the state, they had a – that was their schedule that he's supposed to be plugged in right at 8:00.

**CL:** But when he was first diagnosed with this he didn't have a feeding tube.

**MJ:** No.

**CL:** They put the feeding tube in --

**MJ:** In August.

**CL:** -- it was in August.

**MJ:** Of 2013.

**CL:** Yeah. Yeah, so that's when they put the feeding tube in and – but that's what we've been going through, you know, with them.

**SB:** Yeah, it was always just little things. And other people being, mainly the foster family's family, like being involved. And Diane Tomah, why she was so hard-pressed to keep the child with the foster family is beyond me knowing how hard Mary worked. And I told Mary that all the time, you know my involvement with cases, I don't see anybody work as hard or allow so many people to come in to their house and then everybody to have so many problems, nit-pick. Like they nit-picked her so bad that, I mean, she cried in a couple of meetings, you know, and I don't blame her. I mean, just the exhaustion of her being so open, I was baffled. So –

**CL:** And then after she did get custody back we were at this Harlem – is it Harlem Rockets?

**MJ:** Yeah, that basketball game.

**CL:** We were at that basketball game over here, she brought Molihk, he was in the stroller, and then, when was it, the next day somebody had called the state and said that Molihk was not plugged in.

**MJ:** Yeah.

**CL:** His feeding tube wasn't plugged in.

**SB:** And so the foster family was there.

**CL:** Yeah, and then the public health nurse, we went to Oakland to the doctor's appointment, and then we went there and we told the doctors about it, he was plugged in, you know, and stuff. And I told the doctors, I even told the public health nurse, all they're trying to do is just cause trouble. And then she said, "Oh, no, no, they care about him. They care about Molihk." I said, "You don't know these people."

**SB:** Yeah, and there was – one thing that upset me too was I went for a visit with him, we went to the foster family's home when Molihk was in the home, and I was sitting in the home and I was paying attention to everything that was going on. And the foster mother smoked cigarettes and so does the foster mother's sister. And so while I was standing there, three times, I was only there for maybe an hour and a half, and the three times while I was there they went – Molihk was on the floor with Mary playing and they went and leaned out the sliding door and was standing there and talking to us and smoking right out the door and –

**MJ:** That's what they do.

**SB:** And so medically they said, you know, he shouldn't be around smoke or anything, no child should, but yet nobody nit-picked her for that. Nobody said a word. And in her car it would be all smoky, she'd have the window open like she smokes in the car with him in there.

**CL:** Yeah, that's what she did coming to Oakland.

**MJ:** Yeah.

**SB:** Yep, and so nobody –

**MJ:** And then we bring it to her attention, she was like, oh no we stopped in Lincoln when –

**CL:** Why did his hair smell like smoke?

**MJ:** I know. She's like, oh, no we stopped in Lincoln to –

**CL:** And then every time we try to say something about Beth with the state or the Tribal Child Welfare, “You're only picking on Beth, you know, you're trying to cause trouble on Beth.”

**SB:** Yep.

**RG:** I can pause it.

**CL:** But that's what, every – all the time is we try to say something, you know, about her and stuff and they say oh, no Beth –

**MJ:** You're just picking on Beth.

**CL:** -- you're just picking on her.

**SB:** And she –

**CL:** You know, you're just trying to cause trouble on her.

**SB:** There was two meetings we went to where we were sitting and we were talking and of course I advocate for these guys and they're doing all the right things, like I mean, I – and so they play that Beth card; in the meeting they were like, you know, said something about Beth and she got up and went out of the meeting crying and they stopped the whole meeting.

**CL:** That's when I said, because she's not a relative.

**SB:** Yeah, oh, yeah.

**CL:** I said she's not a relative, why does she have my grandson?

**SB:** Because she wanted him in her home, that's what we were trying to do.

**CL:** And I kept trying to say, you know, she's not a relative. She got -- she was crying, went outside and cried. They stopped the whole meeting.

**MJ:** And Anne Bergan followed her.

**CL:** And Anne Bergan followed her.

**SB:** Who's the Tribal caseworker. They stopped the whole meeting; nobody cared about this was in her interest, not in the foster parent. They stopped the whole meeting for the foster parent.



**CL:** Like we were the bad people.

**SB:** The state and the -- yep.

**CL:** We were bad.

**SB:** Yep.

**CL:** I was like, wow.

**SB:** So what happened was Cheryl is, she's a little, she's a little – seeks out, you know, problem solver, and she called, would call different people and she come on to make a complaint to the Ombudsman, so that was what she did. She called me up and said I'm going to make a complaint to the Ombudsman. I was like that's an excellent idea. So we did, we sat together, Mary, Cheryl, and I here. We –

**CL:** We started, you know, we just got tired of it. I mean, we wasn't being fairly, you know, fairly taken care of, you know, with the state with Molihk and stuff and so we called them and –

**MJ:** So they did an investigation on Kim Tyler and Shannon Prout. They removed Kim Tyler.

**CL:** Yep, they removed her and we got Shannon Prout.

**MJ:** We got Shania.

**SB:** Shania Bella.

**MJ:** Mugford.

**SB:** Oh, Mugford, that's right.

**RG:** Was Shannon Prout still on the case?

**MJ:** Yeah.

**CL:** She's still the supervisor.

**SB:** Supervisor.





**RG:** Okay.

**MJ:** But, you know, they –

**SB:** It helped once Kim Tyler, once they got rid of her because she was in Beth's back pocket. She was the foster mother's ticket to keeping her away from her. So I think the Ombudsman complaint really helped because after that –

**CL:** They said they were opening up the case.

**SB:** Yep, they did open up a case and they got rid of Kim Tyler right off and then once we got – once these guys got Shania –

**CL:** Yeah, Shania. She was real good.

**SB:** -- things changed.

**MJ:** She was real good. Things changed and, you know, I got more –

**CL:** Everything was in the positive.

**MJ:** Yeah, I got more time with Molihk and then about a while down the road I got, you know, overnights, I got, you know, it was Monday through Thursday 8:00 to 4:00 and then Friday, Saturday, Sunday I got overnights. Sunday I would bring him back at 4:00.

**RG:** How long into the case was it before you made a complaint to the Ombudsman?

**CL:** Oh, dear.

**SB:** Gee, it was at least a year in, over a year in. Over a year in.

**MJ:** Yeah.

**CL:** Yeah, we just got tired of it, you know, I mean, it was not fair.

**SB:** Yeah, and on the state – and it was really important because we were on the state's clock then. You know, I mean, with the Tribal Child Welfare I – that's, in this type of case, I appreciated that there was – there wouldn't be a time clock, but once you're on the state's custody you're on a time clock to do the right thing. And she was doing the right thing but nobody was recognizing her efforts because in their mind – they even made them get a psychological evaluation, the state did, required her and the father to get a psych—and then they wouldn't even share the results with them.

**MJ:** No.

**SB:** The state kept them. It took their lawyers to get the – not her lawyer at that.

**MJ:** Not mine.

**SB:** It was the father's lawyer, Carol Lewis, who was fan – if she was not on this case, God help us because she was the one – even though she wasn't Mary's lawyer, because she knew what questions to ask because she was really like, you know. And then when the baby Molihk was failing to thrive in the foster parent's care and so then everybody started realizing, “Oh, well, maybe it's not Mary and maybe the baby just has medical needs that sometimes cause him to not thrive,” and so he has back falls and then he has gains but he bounces and they figured out this is just how this baby, how he's going to grow.

**CL:** Yeah, that's it.

**MJ:** And then at the meeting when I got the good news that I was going to get him back and Beth was all upset.

**CL:** They invited Anne Bergan, Diane Tomah, Beth didn't show up at that last meeting, remember?

**SB:** No, she didn't because I was there.

**CL:** And Steph showed up. Dot didn't show up. Dot –

**SB:** No, Dot showed up. She was there.

**CL:** Oh, yeah. No, no, that's right.

**SB:** Because she was happy.

**CL:** Yeah, she was there too, yeah.

**MJ:** Yeah, I was going to get custody.

**CL:** And the week before – no, a week or two before the Court Shania Mugford came over to Mary's and at the end of the meeting she said, “So if Mary doesn't, we don't, she doesn't get custody back are you still going to go for placement?” I told her yes, I am. She said, “Oh, okay. That's all we wanted to know.” And I was like, okay, you know. And then at that meeting then they did – they told Mary she's getting him back.

**MJ:** Yeah, and then –

**SB:** The state – yeah, they said if she did fight for custody --

**CL:** For placement, yeah.

**SB:** -- then the state was going to step away from the whole case itself, which I was like, what? Here they're making a big deal out of medical and trying to even say she was incompetent and then when they said if you're going to fight for placement then the state is going to back out of the case completely if she gets placement.

**CL:** And then he has a mixture that she mixes with his Pediasure and all that stuff. The doctor wasn't sure about okay, he's still not gaining weight, you know, we need to lower the water. You don't take water away from him. He's nephrogenic, you know, diabetes insipidus, that's the whole thing. And then Eastern Maine almost killed him that one time.

**MJ:** Yeah.

**CL:** He was in the hospital, when was it, February sometime. He was in the hospital and in that IV bag had saline in it and saline's salt, you know, and they said his sodium's going up, why? We asked them is there salt in that bag, you know, they said yeah, it's saline. He's not supposed to have salt. Don't you read his chart? I was yelling at the nurse, "Don't you read his chart?"

**MJ:** I mean, he was diagnosed there. They should –

**CL:** Yeah, he was diagnosed there and they should know, you know, and they said, "Oh, we'll switch it to sugar," you know, so they switched it. I mean, these nurses and doctors, don't they read up what they, you know, these kids have their charts and stuff. I don't know. But we got him back.

**MJ:** Yes (*laughing*). That's all that matters.

**CL:** It took a long year and a half.

**MJ:** Yeah, we got him back a couple days before Christmas.

**RG:** Last year of 2014?

**MJ:** Yeah.



**RG:** Okay.

**CL:** And then you got him back – well, she got him back at home, full custody.

**SB:** She got him at home before Christmas but full custody she got back in March.

**MJ:** In March.

**SB:** This March, yes.

**CL:** March 16.

**RG:** That's excellent, congratulations.

**CL:** That was nice.

**SB:** So nice, yeah. I mean, she did everything. She was keeping journals of everything; pampers, food.

**CL:** We went over to Beth's to go get him, you know, because he was coming back home two days before Christmas, we went to go get him and then she came home with three Pampers; three Pampers, no clothes, nothing to show for it.

**MJ:** No clothes. No shoes.

**CL:** She never bought him nothing, no shoes, nothing.

**MJ:** Nothing.

**SB:** And he's a high-needs child so they get more money. Like that was – it was terrible.

**CL:** Like, three Pampers, what's that?

**MJ:** Just his medical stuff.

**SB:** Oh, and when she would have visitation with him, you know, Mary – of course because she couldn't get no help from the state or anything, she didn't have the child no more, so she was getting no aid for Molihk whatsoever and Beth was getting it all, the foster mother. And so when she would send Molihk with her she would tell her, "Get your own Pampers," like. And she's trying to support herself and her home with the other little girl and she wouldn't even be helpful enough to even send Pampers for the baby.



**CL:** And now Maya is potty trained.

**MJ:** Yeah.

**SB:** The older daughter.

**CL:** She's, what, three. She's potty trained so she doesn't need those Pampers anymore so it's all Molihk.

**MJ:** She's fully potty trained. It's just Molihk that's in diapers.

**SB:** That's so awesome.

**CL:** It took a while but I'm just glad. And we even thanked Shania (*laughing*).

**MJ:** I know –

**CL:** We thanked her for, you know, giving him back to us.

**SB:** And so now the foster, what's the engagement with the foster mother now?

**MJ:** She doesn't --

**CL:** When we went there the foster mother's mother asked us, and Beth was right there too, "Are you going to keep him away from us?" And I was like, "No, you can come visit him anytime you want," you know. And ever since we got him home, nothing.

**MJ:** Yeah, they haven't been coming over. You know, we'll go to the store and --

**CL:** Beth looks at us but that's it, she doesn't smile, she don't wave, she doesn't say hi, nothing.

**MJ:** We'll go to the store and see them in the store and then they'll stop and see him, but that's about it.

**CL:** Jackie said, "Oh, we've just been having vehicle problems so we haven't been over."

**MJ:** Yeah, but Beth's been going over to Bruce's.

**CL:** Bruce's a lot. I think she's kind of checking up on you too. That's why she goes over to Bruce's.

**MJ:** Yeah, because she's been going over there like every day.

**SB:** She might be watching them, so I told them like I think it's trouble for her to be over visiting anyway. It's not that they want to keep him from him but me, as somebody who was able to help and also witness what was playing out, to me it is trouble for the foster mother to be over there visiting because I really feel like – as hard as she's working and she's doing the work, she doesn't want her child to die, she's never wanted her child to die. And to fight, I've never seen a mother fight like this with a child in custody.

**CL:** And she's not even licensed.

**SB:** Yeah.

**CL:** Beth.

**SB:** She was never –

**MJ:** They didn't even do a background check. They just –

**SB:** Put him in.

**MJ:** -- put him in there.

**CL:** Yeah, just put him in there. Because it's Diane Tomah's friend so it's sad, you know, the way this works.

**MJ:** But that's what we've been going through.

**SB:** And it's finally done.

**MJ:** Yes.

**SB:** And they don't need to have nobody over to visit.

**MJ:** No. The state's out of it.

**CL:** And Molihk's doing good. He's up to 23 pounds 4 ounces. He's gaining. He's not going to gain, you know, like a normal baby, like a normal two year old. A two year old weighs, what, 40-50 pounds. He's going to weigh 23 pounds. He's been stuck on 23 pounds for, what, two months now? You know, so he's not going to keep on, he's just going to, you know, he's been stuck on 23 for a while. But he'll go up and down. And we give him his water that he needs; anytime he wants water we give it to him. And then at the hospital they said, "Oh, don't

give him too much water because it's filling him up," but the water is what he needs, you know, that's what he has.

**MJ:** I've been giving him his meds, you know, 8:30 to 8:30 at night. He's on three meds in the morning and then two at night. HCTZ and Indocine at night, and then in the morning he's on HCTZ, omeprazole, and indomethacin so I've been doing that. I've been plugging him in, like, doing his bag, priming it, and stuff and I've been following him around with the pole and stuff so. I do all that (*laughing*).

**SB:** She does really good.

**CL:** She's 22.

**MJ:** I'm 23, geez.

**CL:** 23, she had to grow up fast.

**SB:** Yeah, she does excellent. I'm so proud of her.

**MJ:** I had Maya when I was 19 and I had Molihk when I was 21.

**CL:** She had to grow up fast. But, yeah, Molihk is a learning experience, you know, with his condition.

**SB:** Yeah, because at the beginning that's what started all this is they needed to learn is all. I mean, everybody did. You know, it seemed like –

**CL:** Karen Davis (*phonetic*) is the one they said that he was losing weight and she was worried about him losing weight.

**MJ:** Yeah, we had an appointment.

**CL:** She had an appointment up here. I took my son to an appointment in Bangor and I was in Bangor, we were coming back, we were in Brewer coming on Route 9 and Karen Davis calls us up. She said where are you and I said well, we're in Brewer, we're coming back home. She said, well, you better turn around because (*Inaudible*) is bringing Mary and Molihk because Molihk is being, what did they call it, Molihk is being?

**MJ:** Being admitted.

**CL:** Admitted into Eastern Maine. And so we turned right around and –

**SB:** Oh, that was at the start when –

**CL:** That was at the start of the, you know, before the state and the Tribal Child Welfare got involved.

**MJ:** Because his sodium levels kept climbing and they were wondering why and stuff.

**SB:** But now it's a good schedule.

**CL:** So and then we, you know, we have it under control with his sodium and with the HCTZ that's that water pill. You know, that's a water pill that we give him. And then when I found out about what he has, the nephrogenic, I called her gram, which was in Virginia, I called her up and asked her, "Okay, Molihk has this what Joe has," you know the grandfather. And she said, oh, okay. She said, "You know, I can give you some information," you know, and stuff. And she said when Joe and the youngest brother, there was two of them that had it, you know, Joe – the grandfather and his brother had that, and she said, "Well, when I fed him oatmeal it was shipped in." Because they used to be in the army, you know and stuff, and they had to order his oatmeal, order all his meals and stuff because it had to be like specially made. I was like, oh, okay. And she said, "Well, if you try calling," what was it, where they would diagnosis, Walter Reed. Walter Reed Hospital was where the boys were diagnosed and they said, "they can give you more information," you know, on it and I was like, okay, and I'm still trying to, you know. But she gave us a lot of information. She said, "It's hard to remember 56 years ago," you know, because she couldn't remember a whole lot and stuff and now with remembering and stuff. We're, what's her name, Nancy, the public health nurse, got us into a genetics clinic so we could find out where this came from and stuff so our genetics clinic is in June and hopefully Steph will be able to go too (*laughing*).

**SB:** I'd like that, that's interesting.

**MJ:** June 4.

**CL:** June 4.

**SB:** Cool.

**CL:** Yeah, so that's the genetics thing that we're going to go through with Molihk, you know, find out about everything that he has and, you know, where it came from and we can ask some questions too and stuff. But her gram passed away like not even a month –

**MJ:** Thursday.

**CL:** Thursday.





**MJ:** Last Thursday.

**CL:** Last Thursday she passed away in Virginia and they just buried her yesterday.

**RG:** I'm very sorry.

**CL:** But we're just trying to get through that, and—oh. It's still hard to believe that she's gone because I still want to talk to her, I still want some more information you know about things but like she said, she couldn't remember a whole lot. So but it's been hard but now we're getting to know Molihk. So I'm glad we got him back. But it was a hard battle with the, you know, the state. I hope nobody else has to, you know, deal with that and what we went through.

**RG:** I know you talked about it a little but I'm going to ask. When you think about everything that you guys have gone through, what would you have wanted or needed to have made that situation better for you?

**CL:** Somebody we can talk to. You know, that okay if we – if he is in somebody else's foster care, let's all, all of us, all get together, okay, how can we help him. But it was all about, okay, you guys are not getting along. You need to get along first. I was like do we need to get along or do we want to help him, you know, that's what got me. I mean –

**MJ:** And they're always, you know, talking to Beth and stuff like that. They were always on her side and you know they were never, you know, trying to help Molihk out, trying to bring him back to the, you know, family and stuff.

**CL:** Back into the family.

**MJ:** Yeah, and back into the home.

**SB:** Yeah, and that's what we brought up too in an meeting was like, I told them a lot of these problems I think wouldn't happen if the child was with Cheryl because she would be a team player. If the baby was in kinship care rather than just with some, an outsider like Beth was.

**RG:** Was there a reason why he didn't get placed with you?

**SB:** They were banking on this fight.

**CL:** They gave me – yeah.



**SB:** Cheryl is just like she said, she would confront them and say why aren't – like, putting the salt in the lactated ringer, you know, “Why are you doing that?” And Cheryl would say, you know, you're the ones that should know, but they didn't like that. They wanted her to be quiet.

**MJ:** It made me mad because the child welfare, Diane Tomah and Anne Bergan and me and you we went over to Beth's and we sat down and I guess they wanted Beth to have kinship care and I don't know why they wanted her to have that.

**SB:** Yeah, because –

**CL:** Like, guardian.

**MJ:** Yeah, they wanted Beth to have that.

**SB:** Be the guardian, yeah.

**MJ:** I mean, she's not even family. She's not even, you know.

**SB:** And that was the thing that they were bringing up for a long time is place her with Cheryl and they wouldn't, they wouldn't do it.

**CL:** And then –

**SB:** That was the tribe, even.

**CL:** Yeah, and then I had to get a lawyer, you know, what's his name?

**SB:** Norm Toffolon.

**CL:** Norm Toffolon. I had to get him and then he went a few times to the Court for me and stuff. And then he sent me this letter it was like, “Maine law states that children out of the home have to be in a family, in a family home.” And I don't know if that's what done it either for that letter because it got sent to everybody, you know, and they didn't want me to, you know, go to the – take them to court and okay, this is Maine law. He's got to be with family first. So I don't know, you know, but that would've been helpful if we all did talk. You know, don't nit-pick, don't be negative against us. I mean, let's all work together. That would've been better. And if Kim Tyler wasn't there and if it was that Shania Mugford –

**MJ:** Yeah, it would be a lot better.

**CL:** Yeah, I think it would've been a lot better and don't, like when our backs were turned, don't talk about us.



**SB:** Don't allow the foster parent to talk bad about the family, yes. Like these should've been open forums, more transparency. There wasn't.

**MJ:** And we couldn't like get a hold of Kim Tyler. She was always in (*Inaudible*) office and you know we couldn't get a hold of her.

**CL:** And then a few times the day care, Penny's Day Care wanted us to relay messages to the state, Kim Tyler, you know, for them to call Penny back, you know, for some things. And she couldn't even get a hold of them.

**SB:** The state was inaccessible, you know, for anything that they needed help with it was – but it always seemed like the foster mother was like they had a direct line for her.

**CL:** Yeah, they did. They even had cell phone numbers. Cell phones, you know, and we couldn't even, you know, get a hold of anybody. Yeah, we just got tired of it. I even forgot where I heard that Ombudsman.

**SB:** Yeah, I can't remember you, but when you called me I was like, "Yeah, that's a good" – because I didn't even think of that either.

**CL:** Yeah, and I even got the number. I'm not sure if I seen it on TV, you know, if you're – if there's any problems you're having with the state this is the number to call and it's called Ombudsman and then we called. I made an appointment and then she called me back at a certain date, you know, and then we used the phone here. The principal didn't want us to use the phone here, you know, and she gave me just a regular phone. They didn't have a speaker, speaker on it or anything, so couldn't all talk and hear her, you know, so I grabbed a phone from one of the offices over here and I plugged it in over there and then, you know, she called.

**SB:** It worked out well.

**CL:** And I was glad we – it worked out good.

**SB:** Yeah, it did. It did.

**MJ:** Yes.

**CL:** But now – and then when we were taking him to his appointments we didn't get no help like with gas, you know, or with anything to eat, you know, but I didn't mind that. I mean, he was my grandson so I helped, you know, because I work here and I help gas and stuff every month.

**SB:** How many hours was the trips though for the baby's appointment?

**CL:** Oh, over three hours.

**MJ:** It was like three, three hours.

**CL:** And then that's one way.

**RG:** Three hours one-way?

**MJ:** Yeah. Two hours from here to Bangor so he had to go to Waterville so that's like three hours.

**SB:** And so the foster parent got all the support to go but they wouldn't – nobody supported her. And she was trying to be engaged and do everything they said and nobody supported her. If it wasn't for Cheryl, yeah, it would've been so hard. And they were trying to shut her out. It was awful.

**CL:** And then one time when, you know, we had our appointment – his appointment earlier, we stayed right there, right in Waterville, and then we went to his appointment. But then this other time – oh, I was on the cell phone, I was on my cell phone and I was talking to Kim Tyler, I was trying to talk to Kim Tyler but I couldn't reach her so I had to call Shannon Prout and because his appointment was in Oakland at like 10:00 in the morning and then his other one in Bangor with his –

**MJ:** At that healthcare mall for his ear.

**CL:** Hearing.

**SB:** Hearing test.

**CL:** Hearing test was at like 1:00 or something like that. And then we asked Shannon, Shannon Prout, okay, this is his appointment but we're going to be meeting Beth at the appointment in Bangor for his hearing can we take him, is it okay for us to transport him there?

**MJ:** From Oakland to Bangor.

**CL:** From Oakland to Bangor. And then Shannon said, "Well, this should've been asked, you know, a week ago before his appointment, a week or two ago." And I was like, "Well, I didn't think about it until just now, since we got this appointment can we take him there?" And then she said, "Where's Beth?" I was like, "In the other vehicle," you know, because she was another car over and Molihk was in her car and then she said, "Let me talk to Beth." I said

okay. You know, so I handed Beth the car – the cell phone and then, what's that called, Shannon asked Beth, “Are you feeling stressed out,” and I was like...

**SB:** Yeah, because they could hear.

**MJ:** And then Beth's like no, I'm okay.

**CL:** And then she said – yeah, and then she said would it be okay if they did take him to Bangor and then you could meet them there and then Beth said yeah, it's okay. And then so we took Molihk, we took Molihk and then we went to Bangor. Come to find out he already had his appointment.

**MJ:** Yeah, they didn't even tell us.

**CL:** Beth already took him.

**MJ:** Kim Tyler just called –

**CL:** Beth already took him to his appointment.

**MJ:** Kim Tyler just called us on the road.

**CL:** On the road there, halfway there to Bangor, she calls us and says you know this appointment's already been done? I was like, what? She said, yeah, and I said the mother didn't know nothing about it.

**SB:** And the foster mother didn't say.

**MJ:** Shannon Prout didn't even tell us.

**SB:** Nobody did.

**CL:** They let us take him all the way to Bangor. We were waiting for Beth. You know, we went into the doctor's office and they said no.

**MJ:** He already had it.

**CL:** He already had it.

**MJ:** The Friday before his appointment.

**CL:** I was like, what you know, oh man. And then when --



**MJ:** You called Beth and then Jackie answered and they were already in (*inaudible*).

**SB:** Because they knew there was no appointment so they're sitting there waiting with the baby, probably hoping something medically would happen so they could make another complaint on you.

**MJ:** So we had to bring him all the way home.

**SB:** That's awful, I shouldn't say that.

**CL:** And then another time was when Beth wanted to take Molihk to New Hampshire, you know, because Kurt Meader, her cousin.

**MJ:** Bruce.

**CL:** Bruce Meader, her cousin or I don't know --

**SB:** Yeah, her cousin, first cousin.

**CL:** Yeah, had an appointment there, they wanted to take Molihk and we said, we told them we don't want him out of the state, we don't want him going anywhere. Well, where's he going to go, you know.

**MJ:** So Beth took him.

**SB:** Didn't even – yep. So like their wishes weren't honored.

**CL:** So there's nothing we could've done.

**MJ:** Yeah, so whatever Beth could do, she can.

**SB:** They didn't have any sympathetic ear in the Tribal Child Welfare or in the state to help them understand their position at all.

**CL:** Oh, we had a lot of things going on.

**SB:** Except for the Ombudsman, I think she was – she was sympathetic because after her, things tightened up.

**CL:** Things started, you know, getting better. And then they replaced Kim Tyler and then we went to court and Kim Tyler was there. She said oh, I'm just here because she's the new



caseworker for Mary and then so oh, okay. And then I went over there to introduce myself and stuff and then and she was sitting next to John Hawks, the guardian ad litem, and Shania was right there and she said oh, nice to meet you. She started nice and everything and then she was sitting next to him and she looked back at me like she was, had that look like she was upset at me –

**SB:** She had to soak you in.

**CL:** -- or something, you know. I was like, wow. I was like geez, somebody said something to her, she's changed too. I was like, oh no.

**SB:** Yeah, we were real worried when it changed over from Kim Tyler because Kim had left a really sour taste in our mouth and we thought, Oh my God we're getting somebody that don't know anything and it's going to be not good.

**CL:** And then with the doctors in Oakland the way they were treating Molihk, I didn't feel that, you know, they were doing it correctly and stuff because wanting to take his water away is not good. I mean, get different doctors. If that's what he needs is the water, you know, so I tried getting an –

**SB:** Endocrinologist.

**CL:** -- endocrinologist, Anne Boniface in Bangor, and they said he doesn't need an endocrinologist, it's a nephrologist that he needs, you know, because he's nephrogenic. Nephrogenic means kidneys. And I was like oh, okay. So I'll let it go. And I was afraid that once he was still in the state and still with the Tribal Child Welfare that if we took him to an endocrinologist, Anne Boniface, and then that did get approved for them to see him, they would've turned those doctors against us too. I was like no, I'm just going to wait until everything's all done.

**SB:** Yeah, until it's done.

**CL:** And then we'll go there and see Anne Boniface and then she'll understand where we're coming from, where – you know, she'll be on our side and she'll be just trying to help Molihk out and not be negative of other people telling her negative things about us, I didn't want that.

**SB:** And judging because people when, they'll tell you right out they don't understand something but people were judging them like they were unteachable. You know what I mean, like trying to make it about intelligence and that they couldn't learn and I was just baffled.

**CL:** Yeah, like that Dr. Woods.

**SB:** Yeah. Yeah, these doctors, everybody being just judgmental, it was very -- I was even really scared for them because you see people doing the right thing and willing to learn and reading and learning themselves because people aren't wanting to teach them. And showing how when people with big minds and who have, you know, their clout and their ego can really hurt a family. It's just so scary.

**MJ:** And in the beginning I thought we were never going to get him back because of things were going but I would never give up on him. I kept fighting and, you know, to get him back, so.

**CL:** No matter what it take, we keep fighting to get him back. But that's what, you know, we did. I thought of something a while ago, but I forgot what it was now (*laughing*).

**RG:** No worries. Is there anything else either of you would like to add? Anything else you think is important for the commission to know?

**CL:** Just that, you know, what we went through was hard.

**MJ:** Yeah.

**CL:** I hope nobody has to go through that. But dealing with that and Tribal Child Welfare hopefully other Tribal Child Welfare is not like this one. And then Dolly (?), you know, she got replaced after a while. And then they put Bea in there; Bea Mohannan (*phonetic*) never went to school for anything, she's just learning on the job what Child Welfare does. So it's hard. But that's what --

**MJ:** I mean, it shouldn't have took this long, a year and a half, but we had bad --

**CL:** Because we were at that meeting, that last meeting and Anne Bergan was there, a part of the Child Welfare, and she was there and she said, "Oh, this is the shortest that a baby's been in state custody."

**SB:** Yeah, she did say something like that.

**CL:** It was the shortest time that a child's been in state custody.

**MJ:** Diane Tomah never said anything.

**CL:** No, Diane -- all Diane Tomah was there she said, "Oh, so we shouldn't be in court then." Or we were not, you know --

**MJ:** They're getting him back.



**CL:** They're getting him back, you know, so we don't need to be --

**SB:** Yeah, and I was like we don't even -- I was -- because I was at the point where they didn't need to be involved. They had an interest but it was the state's case now and so I was like people like that shouldn't even be involved, we're already in the state. Like I was like, I wouldn't even have Diane there with the way she was, you know, sneaky with her backtalk, you know, "take that baby, take that baby already."

**MJ:** I know.

**SB:** Just ridiculous.

**MJ:** But Shania invited everybody.

**CL:** Yeah, she invited everybody.

**SB:** Because they had an interest.

**MJ:** But I'm so glad it's over. But if I have another boy (*laughing*), I hope --

**CL:** Not for a while.

**MJ:** Yeah, not for a long time, but if I have another one I hope, you know, they don't take --

**CL:** They said 50-50 chance.

**SB:** That gene.

**CL:** But with this genetics clinic we're going to go to I think it's going to help.

**SB:** I think so too.

**CL:** So we're going to learn a lot. And I'm on this NDI site, it got started in, what, 1976 -- or 2000 something. She stated it. She started out with 300 people, you know, in her NDI group and then now she's got over thousands of people on that NDI site. It's the Nephrogenic Diabetes Insipidus group. A lot of them, okay, "This is what my son's doing or this is what I'm doing, you know, does anybody have any input of what I could do?" Because there was some in there that are taking that indomethacin like Molihk is taking and I read up on it when I was in that group and he was in the hospital last that there was a warning sign on there in bold letter that if you have a family history of heart trouble you should not be on this medication. And that's what I was fighting with the doctors about. But they gave it to him anyway.



**MJ:** They said it's for older people.

**CL:** Yeah, they said it's for older people. You know, but they put him on the medication anyway. And that's what's worrying me, what's going on inside of him every time she gives him the medication. The Omeprazole, Beth Ripley said that he was gagging and he was getting sick.

**MJ:** Yeah, that's why he's on it.

**CL:** That's why he's on it. And they said that he's got acid reflux. I was like acid reflux, I mean, don't you have to like worry or whatever, I mean, what does he have to worry about? He was only a little baby (*laughing*).

**MJ:** I mean, he's –

**CL:** Omeprazole, that's why the doctors put him on it because of his acid reflux.

**MJ:** He don't have acid reflux.

**CL:** You know, and with me, what I thought of when he was puking and Beth was telling me that and it was in the morning, I told her couldn't his stomach be full, that's why he's puking? It's got to go somewhere, you know, if his tummy's full. And I think that's why he was getting sick, is he's got too much in there.

**SB:** Because they make him – they have to force him to eat, that's the thing. They said you have to force him to eat his – he has to have a certain caloric intake.

**MJ:** But it scared me when we went over to Beth's in the morning I was giving him his meds and Beth went in the room to get him and she brought him out, he was gagging, he was getting sick and all of a sudden he stopped breathing, like for like a second or two, and it scared me because – and then Beth said, “Call the ambulance” and mom said, “Call who?” You said call who.

**CL:** I know I didn't get it at first.

**MJ:** I know. Call – so, you know, mom did and then the ambulance –

**CL:** The ambulance came.

**MJ:** -- they didn't rush over.



**CL:** They took a while to come over.

**MJ:** I know, geez.

**CL:** And then we just – that's why I think he was getting sick was his tummy was too full. But the doctor said oh, no, no that's only going in just little drips an hour into that feeding tube.

**SB:** Maybe you could ask them to try it without it too. You could say can we see how he does without it for a little while.

**CL:** Yeah.

**SB:** Just to make sure because I hear what you're saying. We're the kind that don't want to give more medicine than you need to because everything you take is going to affect your organs at some point, and I get that concern. And I appreciate Cheryl's proactive approach. I mean, it's good.

**CL:** Yeah, we just, you know, I go on the internet and stuff and read up on, okay, they want to give him this medication I'm going to read up on it. And that's when I told them when they were taking Molihk out of the hospital is that are you're going to write on there that we're against this medication, right, and they said, yeah, it's on there. I was like, good because if anything happens to him I'm suing you people. I didn't say that but I thought about it.

**SB:** Yeah.

**CL:** You know, because it's not right. I mean, putting him on – doctors just want to put you on medications and then when you get addicted to something, you know, you can't sue them. You can't blame them.

**MJ:** But Molihk's been on the hydrochlorothiazide every since he was diagnosed back in 2013.

**CL:** And my mother-in-law, she said why put him on a water pill, why don't you just give him water. I was like, I don't know, the doctors wanted to put him on that.

**SB:** Pill pusher doctors nowadays, yeah.

**CL:** I don't know, we're just glad we got him back. I hope nobody has to go through what we did. I hope not. It's hard. And then not the control or anything, but just you know he's my grandson and I couldn't even have him because somebody else was dictating where he's going. I didn't like that.

**SB:** I didn't either.

**CL:** And then I think all this Child Welfare should be replaced, you know, Tribal Child Welfare and put somebody in there that's gone to school, you know, about that.

**SB:** Or at least tribal people.

**CL:** Yeah, tribal people.

**SB:** Well, the director now is tribal, it's just she doesn't have no education but the ones that are in there right now, the other ones, the family advocate who didn't really advocate for the family, and Anne Bergan.

**CL:** Leslie's just protecting them. You know, Leslie (*Inaudible*) you know replace them. But try telling them, you know, what we've gone through, they don't want to hear it. So the lieutenant governor, I don't know, but now that we got him back he's going to stay home.

**MJ:** Yes. Yep.

**RG:** I want to thank you both so much for sharing. I hear the tremendous amount of frustration and you are very dedicated and very strong and strong-willed, which is a good thing in cases like this. I'm very happy for you that you have him back.

**CL:** It was a long fight.

**MJ:** Yes, it was.

**CL:** I had good friends, you know, good advocates, so I'm glad.

**RG:** Thank you so much. Do you feel okay for me to stop the recording?

**MJ:** Yes.

**RG:** Okay.

**[END OF RECORDING]**