MONA SELECTS

*Lower-Third*

Mona and Owen.

Mona is the single-mother of Owen, age 5, who has Juvenile Tay-Sachs.

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|  | Title: *He got a raw deal. This isn’t what either of us signed up for.*  TC: 2:50  **Mona**: Owen is the sweetest boy on the face of the planet and always was. Just his demeanor, he is always been extremely empathetic to other children -- like I did have kind of a mixed blessing that I had two and a half years of him as a typical child. [00:03:00:02]  p/u 7:00  When he first started falling, he started like falling on his face out of nowhere and he would look at me like what's happening, why is this happening? And he would get angry and his legs -- and I have -- he has an Olaf doll that somebody gave him and they -- he keep dropping it and it will say various snippets from the movie and he kept dropping it. You remember this -- right bud? He kept dropping it over and over again, trying to get to this particular phrase. And he would only stop when he says I can't feel my legs, I can't feel my legs. [00:07:59:14] and I didn’t get that at the time, It wasn’t until after that I would look back and like oh my god! He is trying to tell me and I didn’t understand I thought he was just a kid playing with a toy, driving me nuts. The way they do you know. But he would keep going and then stop always on that phrase and I didn’t put it together you know. Looking back like that now kills me.  p/u 13:05  I don’t feel like this is what either one us signed up for, I mean he got a raw deal, this is not -- it pisses me off for him. But then again he never gets angry, he doesn’t get. He does, he has moments, I shouldn’t say that. He has had moment; he was annoyed and frustrated and pissed. But mostly he just tries to smile. Mostly he just very glass half full. He gets frustrated when other kids walk away from him in school and he can't follow them. He gets mad but he doesn’t dwell on that parts so, why should I? [00:13:59:08]  p/u at [01:08:56:08]  you can't un-know what you know and you are a better person for having learned the lessons that you learned. But seriously there was no other way, there was no other way. I think I said this at the time too like if you are god and you are on omnipotent you really -- you couldn’t come up with some other way to teach me that? |
|  | **Title: *“Being a single mom: It’s just the two of us.”* TC: 44:48**  I used to always say when he was a baby because it's just the two of us. Just me and you and me and you.///  p/u at 1:09:10  I remember that -- being a single parent I really I don’t think I will go to the women's group next time, because that made no sense for me.  **Interviewer**: Why because they were always bitching about their husbands?  **Mona**: They are bitching about their husbands and I want to stand up and say -- do you know how freaking lucky you are? if you have someone that takes out the trach you got It better than I do. So zip it. [01:09:55:16] you know what I mean. Like I just -- but then again I don’t have the trials they have. I don’t have to fight with somebody, I don’t have to debate you know it's my decision is my decision. I don’t have to debate it with anybody. So you know there is pros and cons. It's just I don’t belong in that room. You know it's different -- I belong to this thing called choice moms the single mothers by choice which is different than parents who end up single.  Because it's just different, it’s a different equation, not better, not worse just different and I kind of feel the same way about that -- it's just the challenges are not the same -- I am not saying that there are more or less of them. But it's not just the same thing. So I don’t imagine that you are going to have a single mother group so I just have to deal with that on my own.  **Interviewer**: Single moms of medically complex children with life threatening -- why don't you found that group?  **Mona**: Because I hope there is no one else. [01:10:56:15] I really do. I hope there are no members to that.  **Interviewer**: Do you feel isolated in your singularity?  **Mona**: I always have though -- I think from day one |
|  | Title: *The quest for the cure: sometimes, I don’t know what to hope for.*  TC: [01:15:56:05]  You know I am hoping for a cure, I am hoping for him to getting better but sometimes I feel like -- in the quiet of our own, how much to leave up to him like if he is on a spiritual level I so hope that he is going to stay and be well and all that sort of stuff but sometimes I don’t know what to hope for, sometimes I don’t know what that means like at what point is he not having fun anymore you know he will have to tell me I guess.  **p/u at 1:22:35 ish**  I don’t know what to hope for sometimes, the idea of losing him all together. The idea of him having this -- gipped out of his life that he was supposed to have you know it pisses me -- pisses me off royally when people say this is who you are supposed to be because its genetic. Bite me, you know what else is genetic? Diabetes, [01:22:54:19] it would kill you faster just because it was easier to cure that doesn’t make this anymore part of his personality and who he is supposed to be than that is of a diabetic.  No, it is not who he is supposed to be this is something that is happening to him, in spite of who he was supposed to be or despite whatever you want to put that I don’t know. That just makes me angry when people say that. I actually had a friend of mine, I don’t go over there anymore say to me because I was talking about the -- various trials and being hopeful and all that, she is like would you really want to? Would you really want? Like seriously did you just tell me my kids is better off dead? Did you really just say that to me like what is wrong with you? |
|  | Title: *My family just doesn’t get it.* TC: [01:17:50:]  he is a happy guy. I feel like I am failing him in -- I would like to be able to do more stuff with him and you know go out more and do more and I’m so frigging tired all the time. ~~And I just don’t know what to do and it’s hard to -- I read him stories and we watch TV and when you are not really getting that much back it is hard to do over and over.~~  **~~Interviewer~~**~~: What do you do to fill back your own wealth? Because that is a lot of giving in that’s a quite lot into taking care of Owen other things you can do or do-do to take care of yourself?~~  **~~Mona~~**~~: No. I think the lack of pushing myself is what I am doing [01:18:56:03] --~~ I allow myself to be a blob because I need it, I need to be. I wish I was doing more with him, I really do but it’s hard to do. We used to visit my family every year in Pennsylvania, we didn’t go this year just because how am I going to drive all his stuff and honestly they don’t get it ~~not to the same extent like that’s one of the major things you get out of the other NTSAD people is -- they become your family where your family can’t be your family anymore.~~ They don’t understand, you spend half the time making them feel better, about it -- it is not helping me at all or they are avoiding you all together because they don’t want to deal with it. They don’t have to and that is their prerogative. [01:19:55:04] So you just don’t, don’t do that anymore. So you need that group of people that get it and there are some things in life that you don’t get until you have been there. |
|  | **Title: *We are not other: It could just have easily been you.*  TC:** [01:35:53:01]  I think my message to people when I am trying to raise funds is -- to help them understand that we are not other, we are you. We are -- it could just as easily have been you. There are people that have five -- I happen to have one child in it, worked out that way. There are people with four-five kids and one of them comes out with this. You could be a carrier, you have no idea. Just because you have three healthy children doesn’t mean that you are not. You don’t know. Also understanding and being able to do something about these conditions will only benefit other conditions that you are familiar with. Alzheimer's and thing that -- people that you know and we are going to be your Guinea pigs, we are going to be the people that are going to be willing to stand up and say, yes I will take that risk, as where you are not.  So it'd be hooves people are a society even if they don’t know anyone or can't relate to us at all, to support us. [01:36:52:23] They don’t know that because they don’t know we exist, I didn’t know he existed. It worries me that those companies because there is something in Europe about the company dropping the med because there wasn’t a big enough profit margin involved. It attacks right off of me -- I don’t know. But yeah I think that we are you and it's not just us and them. It’s a -- we are not other. |