

## Mona and Owen

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

1	<p>TITLE: A mom on how the experiences of other parents influences her own decisions: "I am finding my own way"</p> <p><a href="https://www.youtube.com/watch?v=tVT6mE6mESI&amp;feature=emb_title">https://www.youtube.com/watch?v=tVT6mE6mESI&amp;feature=emb_title</a></p> <p>Description: A mom on how the experiences of other parents influences her decisions: I am finding my own way. I like to gather information from other parents for hypotheticals and mull it over. I'm not one of these people that wants to make decisions in advance. I take it day by day.</p> <p>Transcript:</p> <p><b>Blyth:</b> Are you talking to other parents that you know of medically complex kids to compare notes, or feel in community with them, or anything like that?</p> <p><b>Mona:</b> Not really, no. Because I feel like all of our kids are so different. You can reach out for the people that reach out for advice, and I reach out for advice on particular individual things, but I think it's a mistake to compare because these kids are so different, and it's only going to make you feel bad, or in the past it has. Why am I not able to accomplish x, y, z or... Yeah. I just don't. For me, that's not a healthy thing to do. I get too down on myself for that. Also, you don't really know what you're seeing. You're seeing a slice. You're seeing the slice that they're choosing to show you so it's not really a fair comparator anyway. If I need advice on a particular topic, I'll take it. I think that's the -- you were asking me earlier about the growth piece -- that for me has been the biggest... I like to gather as much information as possible for the hypotheticals and mull them over. I'm not one of those people that likes to make decisions in advance. I don't want to make decisions in advance about anything because I think, for me, I need to be in the moment for that decision to mean anything. It's going to change 600 times. That said, I do think it's good to look at everybody's situation and contemplate what they did, and what their choices are, and what their take home interpretation of it was because that may or may not be applicable to you at some point. So that's that way I... I like to have all the possibilities floating around in my head and then when the moment comes, I'll see what feels right.</p>
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	<p>Having an answer to these questions in advance may be helpful for some people -- and I'm not pushing against that for those people that want to do that -- but for some people, that's an incredibly bad idea and you need to respect that too. I just take it day by day, situation by situation, this is the problem we are having today. Although, I did start asking myself, at what point is this more for me than for him, and I do look at families that do make the very difficult decision to stop. I think that takes a level that I'm not... We're not there yet, and thank goodness we're not there yet, but the closer I get to it, the more I understand it.</p>
2	<p>TITLE: He got a raw deal. This isn't what either of us signed up for.</p> <p><a href="https://www.youtube.com/watch?v=Oo7sydpP_0k&amp;feature=emb_title">https://www.youtube.com/watch?v=Oo7sydpP_0k&amp;feature=emb_title</a></p> <p><b>Mona:</b> Owen is the sweetest boy on the face of the planet and always was. Just his demeanor, he has 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.</p> <p>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 at his legs -- and I have -- he has an Olaf doll that somebody gave him and they -- he kept dropping it and it would 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 it says "I can't feel my legs, I can't feel my legs." I didn't get that at the time, it wasn't until after that I would look back and be 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 at that now kills me.</p> <p>I don't feel like this is what either one of 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 moments where he was annoyed and frustrated and pissed. But mostly he just tries to smile. Mostly he's 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 those parts so, why should I?</p>

	<p>You can't unknow 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 omnipotent, you really -- you couldn't come up with some other way to teach me that?</p>
3	<p>TITLE: "Being a single mom: It's just the two of us."</p> <p><a href="https://www.youtube.com/watch?v=r-kdsKXiw1E&amp;feature=emb_title">https://www.youtube.com/watch?v=r-kdsKXiw1E&amp;feature=emb_title</a></p> <p>Description: The mother of a 5 year-old boy with juvenile Tay-Sachs talks about how it has just been she and her son, conceived via IVF, since the beginning, and how it isolates her even further.</p> <p>Transcript:</p> <p><b>Mona:</b> 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> <p>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.</p> <p><b>Interviewer:</b> Why because they were always bitching about their husbands?</p> <p><b>Mona:</b> 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 trash you've got it better than I do. So zip it. 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, it's my decision. I don't have to debate it with anybody. So you know there are 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. It's 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'm just have to deal with that on my own.</p> <p><b>Interviewer:</b> Single moms of medically complex children with life threatening illness why don't you found that group?</p>

	<p><b>Mona:</b> Because I hope there is no one else. I really do. I hope there are no members to that.</p>
4	<p>TITLE: The quest for the cure: sometimes, I don't know what to hope for.</p> <p><a href="https://www.youtube.com/watch?v=ZmS9gVYKDks&amp;feature=emb_title">https://www.youtube.com/watch?v=ZmS9gVYKDks&amp;feature=emb_title</a></p> <p>Description: The mother of a 5 year-old boy with juvenile Tay-Sachs talks about the ambivalence that comes with having a child whose disease is progressing and hoping for a cure that may not come in time. "This isn't who he is supposed to be. This is something that is happening to him."</p> <p>Transcript:</p> <p><b>Mona:</b> 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> <p>I don't know what to hope for sometimes, the idea of losing him all together. The idea of him having this -- jipped 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 it's genetic. Bite me, you know what else is genetic? Diabetes, 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 of a diabetic.</p> <p>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 however you want to put that, I don't know. That just makes me angry when people say that.</p>
5	<p>TITLE: My family just doesn't get it.</p> <p><a href="https://www.youtube.com/watch?v=UOo_VyJIIVA&amp;feature=emb_title">https://www.youtube.com/watch?v=UOo_VyJIIVA&amp;feature=emb_title</a></p> <p>Description: The mother of a 5 year-old boy with juvenile Tay-Sachs talks about the isolation, how her family just doesn't understand, how she has stopped making the</p>

effort to visit them, and how ultimately one needs to be with people who have 'been there' themselves.

Transcript:  
**Mona:** He is a happy guy. I feel like I am failing him -- I would like to be able to do more stuff with him and you know go out more and do more but I'm so friggin tired all the time. 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. 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. So we just don't, don't do that anymore. 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.

6

TITLE: We are not other: It could just have easily been you.

[https://www.youtube.com/watch?v=wK2c4bUxEJQ&feature=emb\\_title](https://www.youtube.com/watch?v=wK2c4bUxEJQ&feature=emb_title)

Description: The mother of a 5 year-old boy with juvenile Tay-Sachs talks about how rare disease could happen to anyone and therefore everyone should care.

Transcript:  
**Mona:** 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 things 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, where you are not. So it'd behooves people as a society even if they don't know anyone or can't relate to us at all, to support us. They don't know that because they don't know we exist, I didn't know we existed.

	<p>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 -- a tax write-off maybe -- 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".</p>
7	<p>TITLE: A mom on decision making: Trust yourself. It's your job. Don't give your power away.</p> <p><a href="https://www.youtube.com/watch?v=Bj7odwDczuY&amp;feature=emb_title">https://www.youtube.com/watch?v=Bj7odwDczuY&amp;feature=emb_title</a></p> <p>Description: In her Zoom call with CPN, Mona, mother of an 8-year old boy who has juvenile Tay-Sachs, shares her approach to decision-making: it's hard to do because you're trying to make a decision about things that haven't happened yet. Trust yourself. It's your job. Don't give your power away.</p> <p>Transcript:</p> <p><b>Blyth:</b> Since I talked with you last, which was a couple of years ago, some of the decisions you've have to make about Owen's care and what has helped you in the decision making --</p> <p><b>Mona:</b> I was surprised by some of the -- I think this goes back to me not wanting to make decisions in advance type things -- so he ended up with hip surgery. Which I remember, I think Isaac had had hip surgery, and at the time when she was doing it, I remember thinking I would never do that because why would you do that to a terminally ill child. That seems like an awful lot to put the kid through and why would you do that... And then, when the moment came I was like, why would you not do that. It was a completely different thing, so that was surprising to me. Again, it just goes back to my ~I'm not making any decisions in advance~ decision. So that's been the big one for me. I try to gather as much information as possible.</p> <p>Try not to make decisions based on just what your doctor says too, or even on what your kid looks like now. I think that is one of the things too. So, he... Owen does not have the -- I don't know what it's called when they do the... when they do the G-tube and then they tighten it so you can't puke..? The fundila something...? --</p> <p><b>Blyth:</b> Oh. I know what you're talking about. I won't be able to say the word either.</p>

	<p><b>Mona:</b> So I think that I probably -- and at the time I remember them saying that he doesn't need that, and he didn't need it, but I probably should have done that because we wouldn't be having these events that we're having now -- what I've learned is that you can't think about just his moment now. The difference between the short term decision and the long term decision, you have to consider the long term decision. Don't just look at what the kid looks like now, you have to consider what is going to be best ever. I think that it's hard to do because you're trying to make a decision about things that haven't happened yet -- I'm contradicting myself right now -- but it's... you do have to weigh the worst case scenario options in with what you're doing now because it's not an isolated thing. It's going to keep going if you're talking about a progressive condition so -- am I making sense or am I babbling here? --</p> <p><b>Blyth:</b> No, you're making sense, you're making absolute sense. I mean some anticipation... I mean this is true of parenting, right? In any parenting we need to anticipate as much as possible what will be best for our children and make decisions in the moment that will play out well.</p> <p><b>Mona:</b> Take all the advice, listen to what everyone has to say, and at the end of the day, make your decisions for yourself and trust yourself. Don't -- God, the universe, chance, whoever entrusted this child to you. It's your job to make these decisions. What you feel is right, is right and you need to trust that -- don't give your power away even in those times when it would be easier to do. Just don't do it. Those are the only regrets that I have, the points where I can look back and think, I should have done what I thought I should have done, I should have said what I thought I should have said. Making a mistake is one thing, relinquishing the power to somebody else's mistake is something else. It's a harder thing to live with I think, for me.</p>
8	<p><b>TITLE:</b> A single mom on finding support: Bringing my sister up to speed.</p> <p><a href="https://www.youtube.com/watch?v=BhGsTnTsBv4&amp;feature=emb_title">https://www.youtube.com/watch?v=BhGsTnTsBv4&amp;feature=emb_title</a></p> <p><b>Description:</b> A single mother of an 8-year old boy with juvenile Tay-Sachs talks about how her family doesn't get what it is like for them; and what it is like to bring her sister into her reality, to catch up. "She has become my person emotionally, but she's not ready for that."</p> <p><b>Transcript:</b></p> <p><b>Mona:</b> My family don't get it at all. I sort-of stuck my toe in there recently -- I think it was after one of these events, the EMT events -- it was a lot. It was... I was awake</p>

	<p>probably for 48 hours just watching him breathe and just making sure he was okay. It was like mom ICU and I was pulling a double, you know. It was exhausting and he was exhausted and I was exhausted and it was just, how many more of these do we have in us? How many times can you do this? And I expressed that to my sister-in-law and she was like, “oh my god you need to talk to somebody. Is there a psychiatrist you can talk to...?” because this was brand new to her. I’m like, sweetie, this is Tuesday to me. I just voiced it to you, that’s the only thing, and now you’re making me regret it. So I had to -- she’s like, “you need to talk about it” and I’m like, “no, I just did talk about it. That was the extent that I want to talk about it. You need to calm down.” I think I have been sheltering her a little I think so I’m trying to give her a little bit more reality, a little bit more of the ugly than I had been in the past just so that she can catch up. I think at this point she has become my person emotionally, but she's not ready for that.</p>
9	<p>TITLE: All of my decisions are about getting him to the clinical trial</p> <p><a href="https://www.youtube.com/watch?v=0tIq3_r13wU&amp;feature=emb_title">https://www.youtube.com/watch?v=0tIq3_r13wU&amp;feature=emb_title</a></p> <p>Description: A single mother of an 8-year old boy with juvenile Tay-Sachs shares that every decision she now makes for her son, including tracheostomy, is about giving Owen the chance to receive gene therapy.</p> <p>Transcript:</p> <p><b>Blyth:</b> Have you had to consider a tracheostomy to help with respiratory issues or not?</p> <p><b>Mona:</b> So, one of the times when we were in the hospital not too long ago, it came up. It didn’t end up happening, but it came up. They were talking about a trach vent. It didn’t have to happen, but they threw it at me just as something to contemplate. Again all of my decisions are about getting him to the trial. That’s my goal. If I felt like -- and there’s a difference there to me, do I put him through that or not -- if it’s going to bridge me to getting him gene therapy, then yes. If it’s not going to make any difference one way or the other, why? That is a huge, I can’t ignore the potential for gene therapy because again, that has always been my goal, always been my goal. All of my decisions are informed by that eventuality.</p> <p><b>Blyth:</b> I’m really hearing how complicated and bound up all the decisions are in things that are... you have control over some decisions but you don’t have control over things that will trigger the decision, so how do you make the decision? That’s just -- as I just explained it that’s impossible</p>



	<p><b>Mona:</b> Well exactly. That’s why I get so angry with the whole... I need that piece to just be so I just put it in my head as a, yes that’s happening. If I have to move heaven and earth, that’s going to happen because I need that to not be a variable, it needs to be a given. So, therefore it is.</p>
10	<p>TITLE: A mom on how the experiences of other parents influences her own decisions: “I am finding my own way”</p> <p><a href="https://www.youtube.com/watch?v=tVT6mE6mESI&amp;feature=emb_title">https://www.youtube.com/watch?v=tVT6mE6mESI&amp;feature=emb_title</a></p> <p>Description: A mom on how the experiences of other parents influences her decisions: I am finding my own way. I like to gather information from other parents for hypotheticals and mull it over. I'm not one of these people that wants to make decisions in advance. I take it day by day.</p> <p>Transcript:</p> <p><b>Blyth:</b> Are you talking to other parents that you know of medically complex kids to compare notes, or feel in community with them, or anything like that?</p> <p><b>Mona:</b> Not really, no. Because I feel like all of our kids are so different. You can reach out for the people that reach out for advice, and I reach out for advice on particular individual things, but I think it’s a mistake to compare because these kids are so different, and it’s only going to make you feel bad, or in the past it has. Why am I not able to accomplish x, y, z or... Yeah. I just don’t. For me, that’s not a healthy thing to do. I get too down on myself for that. Also, you don’t really know what you’re seeing. You’re seeing a slice. You’re seeing the slice that they’re choosing to show you so it’s not really a fair comparator anyway. If I need advice on a particular topic, I’ll take it. I think that’s the -- you were asking me earlier about the growth piece -- that for me has been the biggest... I like to gather as much information as possible for the hypotheticals and mull them over. I’m not one of those people that likes to make decisions in advance. I don’t want to make decisions in advance about anything because I think, for me, I need to be in the moment for that decision to mean anything. It’s going to change 600 times. That said, I do think it’s good to look at everybody’s situation and contemplate what they did, and what their choices are, and what their take home interpretation of it was because that may or may not be applicable to you at some point. So that’s that way I... I like to have all the possibilities floating around in my head and then when the moment comes, I’ll see what feels right.</p>

	<p>Having an answer to these questions in advance may be helpful for some people -- and I'm not pushing against that for those people that want to do that -- but for some people, that's an incredibly bad idea and you need to respect that too. I just take it day by day, situation by situation, this is the problem we are having today. Although, I did start asking myself, at what point is this more for me than for him, and I do look at families that do make the very difficult decision to stop. I think that takes a level that I'm not... We're not there yet, and thank goodness we're not there yet, but the closer I get to it, the more I understand it.</p>
<p>11</p>	<p>TITLE: A single parent, at home, with no help, in the time of COVID</p> <p><a href="https://www.youtube.com/watch?v=8amdiWUMvcY&amp;feature=emb_title">https://www.youtube.com/watch?v=8amdiWUMvcY&amp;feature=emb_title</a></p> <p>Description: A single mother of an 8-year old boy with juvenile Tay-Sachs talks with CPN via ZOOM about what it's like for her: no more nurse, comfort with social isolation, leaning on the EMTs, and loving telemedicine. Recorded in May 2020.</p> <p>Transcript:</p> <p><b>Blyth:</b> So I am here with Mona Vogel, mother of Owen, who we spoke with - interviewed - several years ago for Courageous Parents Network, and for National Tay-Sachs, and I am really grateful to Mona for agreeing to talk with us again today. We are going to be talking to you Mona, asking you some questions about what it's like to be caring for Owen at home during this time of COVID and what's coming up for you. I'm wondering how you would describe this time for you and Owen. How COVID has affected... in what ways has covid affected your life?</p> <p><b>Mona:</b> So, one of the first... early on I actually asked his nurse -- I made the decision to ask his nurse to not come anymore. I was on the fence about it and in the beginning, it was, am I overreacting, am I underreacting? I don't think anybody really knew. I actually reached out to his pediatrician as well. The difference was with my nurse, while I think she would never intentionally harm him, she was young and insisted on hanging out with her girlfriends for one other their birthdays. The pediatrician was like, well, that's a different mindset if you've got a bunch of young people who don't see the problem with getting together for a social occasion, then they're probably not being as careful as other people. So unfortunately, I posed it to her like I don't mean to ask you to choose between your social life and your job, but I suppose I'm asking you to choose between your social life and your job, and she wanted to go out. But, she understood where I was coming from also.</p>

She lives with her dad who works at a nursing home, which at the time I wasn't worried about because they were being extra careful, but now I'm thinking in the long run that it's probably for the best because try as they may, nursing homes are hotbed for carriers.

The long and the short of it is, it's just us in the house on a day-to-day basis so I'm not getting any break at all which makes simple things like taking the trash out a big deal.

\*Next clip\*

TITLE: We've been isolating anyway. I know how to do this

Transcript:

**Mona:** There were two times actually that I ended up calling 911 then didn't go to the hospital, because who wants to go to the hospital under these circumstances. A) he's not going to be anybody's priority, B) he's going to just be exposed to a bunch of crud that he has no business being exposed to. Also, the good news I guess is that being a medically complex family, I know what to do. I know the drill. I know how to do this. So, yeah, it was just all me.

Fortunately for me, the EMT's were totally on board with that. They weren't trying to force me or talk me into going in at all. But it was scary... It's scary in the moment when going to the hospital is not really a viable option right now because you're just not going to do that. It's just a bad idea.

**Blyth:** So Mona, when you said... a minute ago when you said, "I know how to do this" do you mean you know how to take care of Owen in an extreme situation or I know how to be socially isolated?

**Mona:** Both! I think it's because being socially isolated... I've been socially isolating him since basically the beginning of this year. I mean I had no idea the extreme but I knew this year's respiratory bugs were worse. He went out earlier in the year because he had to have the hardware from his hip surgery removed, so I took him out for that because I didn't want him getting sick going into that. Then he hasn't been back to school since because I was touching base with the primary care and asking -- I always do -- asking her What's the flu season like? What's going on? And it just seemed like upper respiratory stuff, there were too many cooties floating

around this year. So we really, I didn't really -- I didn't know the half of it -- but we were kind-of socially isolating anyway.

So, this I think to some degree is a little bit easier on medically complex families in that it's not that far off our normal. This is what we do. We also have a lot of the equipment that they're scrambling for. We have globes, we have masks, we have purell, I have a bi-pap in the house. So we're a little more prepared than the average person mentally and physically as far as stuff goes.

\*Next clip\*

TITLE: Yes, we would go to the hospital if need be; but the EMT's help me get him stable.

Transcript:

**Blyth:** Thankfully, you are an expert. You know what Owen needs and you have had to learn how to do all of those things, and you can. No one knows how to take care of Owen better than you do, and there you are. That having been said, and I hope you don't think this is an upsetting question, but would you take him to the hospital if there was an emergency or are you determined not to take him?

**Mona:** No, I would. Actually, the first time that that happened I was -- under normal circumstances I would have gone in, I would have just let them take us in -- so I did feel kind-of guilty about that. I'm very fortunate in that his pulmonologist, I have his personal phone number, and I text him constantly and he's very good about getting back to me. I was asking him, because you do wonder, at what point am I being irresponsible by not bringing him in? I was just keeping him updated as to what was going on and he said, -- just because of the nature of the hospital and the amount of beds that they had -- "unless he gets significantly worse, they wouldn't take him anyway." So, as long as he's stable and improving I don't think that they would take him away. That's where we were.

When I call the EMT's, I want them here until at least we can get him stable, and until at least I'm at a place where, he may not be his baseline, I may have to work him back, wean him down on the O's, wean him back on the pressure, you know, do the whole extra suctioning, and extra pulmonary toileting, and the whole shebang that you have to do, but at least he's stable and I think that's all he really needed to be.

**Blyth:** So, the EMT's will come and help you in that acute moment and then they leave.

**Mona:** First of all, they know us. It's not like this big... They've been here before so they know him, they know me, they know my level of competency at this point so I think that helps. There was one time, the first time, I actually waited a while before I called 911 because I didn't want to go and I was telling the dispatcher this and he was like, "we're not going to force you to go... we might make to sign something..." and he must have relayed that to the guy so that by the time they got here, I just think on a personal level they agreed with my assessment so they didn't push it at all and they understood that they were there really for emotional support more than anything else.

Thes second time this happened, they came and they were here for a long time. The only thing different was that he was requiring more oxygen than I could supply. Mine only goes up to ten and he was requiring like fifteen for a little bit just to get over the hump but then we weaned him down and he was fine.

\*Next clip\*

TITLE: I am loving telemedicine

Transcript:

**Blyth:** What about telemedicine? How is that? How are you getting it --

**Mona:** Loving that. Loving that. I ended up getting a differente GI doctor who I've only ever seen via phone calls at this point. We'll meet him eventually but thus far it's only been via the phone. His pulmonologist and his neurologist we've done -- children's hospital has a telemedicine thing, I guess it's a Zoom but it's specific to them... I love that. It's just, I hope to continue with that. I hope that they can come up with -- again, somebody local has to have hands on but -- and another example of why I love the pulmonologist is -- in the past when the primary is like, "well you really need to see the pulmonologist" and the pulmonologist is like, "you really don't need to drag him all the way out here, I'm not going to hear anything different than they do." So he was perfectly willing to take their description of what they're hearing and feeling and I think that that at baseline for our kids outside of this COVID-19 would probably be preferable because dragging our kids around from

doctor appointment to doctor appointment is hard on them, it's hard on us... You're not seeing the kid at baseline anyway, you're not seeing the parents at baseline, by the time we get there.

So, that's been really a bonus of all of this and I hope it stays in place. The same goes for school as well, so his teacher has been doing two Zoom sessions a week and I'm able to just put Owen on it, and he's able to stay home and be with the other kids and interact and get all of that, which he has missed a lot of this year just because I was social distancing him, but I hope going forward that that would continue to be an option.