

## Sarah and Melissa

Mother and Grandmother of Emerson, who had Gaucher Type II and died at age 16 months.

1	<p>TITLE: Most of my attention went to my daughter, not my granddaughter.</p> <p><a href="https://courageousparentsnetwork.org/videos/most-of-my-attention-went-to-my-daughter-not-my-granddaughter/">https://courageousparentsnetwork.org/videos/most-of-my-attention-went-to-my-daughter-not-my-granddaughter/</a></p> <p>Description: This video is about how most of this grandmother's attention went to her daughter, not her granddaughter.</p> <p>Transcript: <b>Melissa:</b> I am Melissa Hall. I'm Sarah's mother and I was Emerson's grandmother and still feel as though I am her grandmother. She was my only granddaughter.</p> <p>For me personally, that's the worst thing that can happen to you. Because I'm fairly concrete and I'd like to know what it is, what's our goal here to fix it and how do we get there and then fix it. This I couldn't fix.</p> <p>So when this happened with Sarah, and I heard the diagnosis, it was almost like I can't start crying. I can't kind of lose my way here. I need to stay together and focused and do what I can to help. I also need to take a step back; not rush in with my pointer finger and say --- here's what we're going to do to make this you know --- find out everything we can about this and make it the best we can make it. Because I was afraid if I did that, which I could have, I wanted Sarah and Steve to stick together and work these things out themselves. Because I think at that point, they were so, and I was too except I thought somebody has to watch over them, and so I kind of stepped back and I tried to be supportive when I could be.</p>
2	<p>TITLE: I did the little things that I could do, like watch Emerson so they could have a date.</p> <p><a href="https://courageousparentsnetwork.org/videos/i-did-the-little-things-that-i-could-do-like-watch-emerson-so-they-could-have-a-date/">https://courageousparentsnetwork.org/videos/i-did-the-little-things-that-i-could-do-like-watch-emerson-so-they-could-have-a-date/</a></p> <p>Description: A grandmother of a little girl with Gaucher Type 2 shares the ways she found to be helpful without being too involved (aka bossy!) or</p>

being able to actually fix the disease. The mother talks about how helpful her mother was with her daughter. "She had a real connection with you."

Transcript:

**Melissa:** Because I live so far away, I was concerned, I was concerned for my daughter and Steve. They were in Burlington. They really didn't know anybody. She had her one friend, Meg. I've known Meg since she was probably what, six, seven -- around that age. She is lovely. But other than that, there was nobody. They knew nobody up there. I always feel better when I know that my children, who are not children anymore, have good people around them because then I know that they are ---you know that they are in a good place. I would try to go up there, maybe once a month for the weekend. I don't like it when there is nothing I can do. So I'd say what can I do. So I would go and I would do laundry and I would make breakfast and I would pick up. One of the first things I did when I went up there. I said to them -- okay, I'm here. This was probably a month and a half after.

**Sarah:** After the diagnosis.

**Melissa:** After the diagnosis and of course they were, as you know, you know. So I went up there and I thought I'm going up there and I'm going to stay with Emerson and they're going to go down to the restaurant just the two of them and get out of that apartment and go do something other than be ---

**Sarah:** Because we hadn't brought our house yet, so we were still in the apartment.

**Melissa:** I don't think they had been out of the apartment for weeks. So anyway, I went up there and I told them they had to go. They said -- no, they weren't going to go. I said --- this is what I did, because I couldn't do anything else. I said yes, you are going to go and they said, no, we can't leave Emerson. I said I'm a registered nurse and I'm your mother. You are not going to be more than six miles away. If anything happens, I can either call you. If they can't hear the phone ring, I can put her in the car and take her to you just to show you that there is something wrong. I think it will be fine, so you're going to go, and they went. I almost had to push them out the door. But they did go. So those are the things I tried to do for them.

**Sarah:** Emerson loved her, like, a lot.

**Melissa:** She did love me.

	<p><b>Sarah:</b> We think sometimes like because you would come and do laundry or send us to go to diner or, we didn't let anybody feed Emerson, because sometimes she had trouble swallowing. Nobody could -- well, we didn't let anyone really do anything with her, but you could. So then we would get a little bit more relaxed even without noticing. Emerson, when she would see my mom, would start smiling and laughing and reaching out to her and having a great them.</p> <p>Steve and I would be like -- no, you need us. We're the ones; you know just jokingly. But I think that in some ways, it did lower our stress to have someone kind of in-charge I guess. I think Emerson felt that because she would always be -- also, I think she just had a connection with you beyond that.</p> <p><b>Melissa:</b> I think so.</p> <p><b>Sarah:</b> But I think that, that was really helpful.</p>
3	<p>TITLE: "I couldn't imagine how much pain Sarah was in. I could only go along with it."</p> <p><a href="https://courageousparentsnetwork.org/videos/i-couldnt-imagine-how-much-pain-sarah-was-in-i-could-only-go-along-with-it/">https://courageousparentsnetwork.org/videos/i-couldnt-imagine-how-much-pain-sarah-was-in-i-could-only-go-along-with-it/</a></p> <p>Description: A grandmother of a little girl who died from Gaucher Type 2 acknowledges that she could never fully know her daughter's pain. Her daughter, the little girl's mother, talks about how her mother's strength helped her get through. "We felt taken care of."</p> <p>Transcript:</p> <p><b>Melissa:</b> One of things was Sarah was feeling very much like this was one of the worst things that could ever happen to anybody ever on the face of the earth. So we had conversations about that, and I tried to start with --- anyone who loses a child, it's all wrong, it's all wrong. I talked to people that are 80 years old in the hospital who lost children when they were three years old and it still makes them cry. I said for someone who loses a child at 10, 12, 20, 25; to me, this is my thought. I've never had the experience and I pray to God that I never do. The loss of a child is a loss of a child. One of the other things that I would talk with Sarah about, was that she would say well you don't understand what I'm going through, and I would say no I don't. It was a goal of my life to never know that. You work your whole life to keep you kids safe and and on the right track, and try to keep most things from hurting them that aren't gonna be</p>

	<p>as beneficial as the hurt that they bring. And I said you know I tried to go and think in that place what would I do if it was me, and it is so terrifying. I said people can't go there. They can't go there to even try to get the feeling because the thought of even in your imagination pretending that you lose a child, you can't do it. I couldn't. I couldn't; it's too terrifying. So could I understand where she was – no. Could I feel the pain that she was going through? That's what I was feeling. I couldn't do anything about that either, except kind of go along with it, and I don't like that. I like to fix things.</p> <p><b>Sarah:</b> I think I was grateful that she would be obviously be caring and compassionate, but sometimes would be able to --- I wouldn't say do a reality check, but it wasn't like that, but to just to kind of help me sometimes get out of my own head when I was kind of stuck in a spot where I couldn't kind of step back and just take a break from this thought or this feeling that was just -- - I was stuck on. I think that for me, I can speak for Steve to some degree too, I think that it would have been really hard if my mother was someone who was taken down by her grief that then we were having to feel like we had to take care of her grief. So sometimes, I think now we look back and see that ---some of the times I would get upset thinking she was having a tough exterior or having you know or not indulging in being like --- you're right and then we both just cry and fall apart and say everything is terrible. I think that we appreciate that we didn't have to feel like --- we felt taken care of but at the same time I don't know that --- we were always so in what we were doing with Emerson, I don't know that we always acknowledged what she was going through.</p>
4	<p>TITLE: "I spoiled my granddaughter!"</p> <p><a href="https://courageousparentsnetwork.org/videos/i-spoiled-my-granddaughter/">https://courageousparentsnetwork.org/videos/i-spoiled-my-granddaughter/</a></p> <p>Description: The grandmother and mother of a little girl with Gaucher Type 2 laugh at how even during Emerson's short life, she still got to be spoiled by her grandmother.</p> <p>Transcript:</p> <p><b>Melissa:</b> I would give her all the stuff I wanted to give her.</p> <p><b>Sarah:</b> I came home and they were watching like some crime show. I was like – what is she watching? My mom was like, she likes it. I was like ---- I think we were going to give her some juice or something. We tried to give her all healthy stuff because we were trying to keep weight on her.</p>

	<p><b>Melissa:</b> Coca Cola.</p> <p><b>Sarah:</b> She was like --- I gave her soda. I was like what.</p> <p><b>Melissa:</b> She liked it.</p> <p><b>Sarah:</b> She was like she really wanted to try it. Even though we said we gave her anything she wanted. We didn't; there were certain things like that. I think that sort of like typically you think of a grandparent. They give them the candy before they send them home or they give them whatever. Even in Emerson's short life, she still got to have that relationship too. Even though we were saying we let her do what she wants. She doesn't have any rules, because we just want her to be happy all the time. Even with that, my mom would do things like that and I would be like you can't do that. She's 12 months old. In some ways, we had a normal relationship around that in the midst of it, which was kind of funny.</p>
5	<p>TITLE: My concern was for them as a couple.</p> <p><a href="https://courageousparentsnetwork.org/videos/my-concern-was-for-them-as-a-couple/">https://courageousparentsnetwork.org/videos/my-concern-was-for-them-as-a-couple/</a></p> <p>Description: The grandmother of a little girl with Gaucher Type 2 talks about how her biggest concern was for her daughter and her daughter's husband to stay together and be OK as a couple. She also shares how unnatural it was to say, "My daughter's daughter is dying," and not be able to do anything but support her daughter.</p> <p>Transcript:</p> <p><b>Melissa:</b> my concern too was I wanted Steve and Sarah to stay together. I didn't want them in their grief and their pain to kind of go this way as a lot of people do or to disagree on. Not that I could control that, but I wanted to make sure that they --- I wasn't in there going now you're going to do this, this and this. Tomorrow, we're going to get this done and that done and we have to put this in that, because of the time. I could have gone in there and taken over the whole house. So I tried not to do that. I did a Good job.</p> <p><b>Sarah:</b> You didn't take over.</p> <p><b>Melissa:</b> No, no--- That's what I tried to do and make sure that they</p>

	<p>were okay. I think just to be there. I think to acknowledge the fact that it's okay to have your focus on your child, because that's your child. That was her child. A lot of focus on her too and I adored her. She was funny, funny, and she was very happy. She really wasn't sick until the end. But to be brave enough to be able to say my child's child is dying, it's so inappropriate and so wrong and so backward, but that's what's happening. Being able to without ---going what about me. You haven't asked how I am. You haven't heard how much anxiety I have. Do you understand what I'm going through? Don't you know. We are supposed to bring them up and set them free. Like I said to them, go. Go, get a life. Go, get a life, but at the same time – go get a life but put a string if I need to pull you back. To know that help is just in being there for the support. I think being there and the support and knowing when to say to them when they say – no, I'm not doing that. To be able to say, you know what tonight you are, tonight you're taking a break from only being supportive and I'm going to tell you what you're going to do. I think the parents need the opportunity to step out of that situation even if it's for two hours to go down the street and sit on the bench if that's what they want to do or go to a restaurant or go. Just to kind of so it's the two of them. Sometimes, it works out good. First time they went when they didn't want to, they came back and said it was the best thing you ever did for us. Next time they did it, they came back and said --- it was like the bombing of Saigon. Because they came back and I guess they had a discussion at dinner that wasn't quite as pleasant as the first one. But it's still good to be able to do that without anybody else. I can only say that's what I believe. That's what people need to do. That's what I thought I could do for them. They thought I was good to not step in and start ordering and telling them the best way to do this or how to do it. The concern is with the couple.</p>
6	<p>TITLE: I'm inspired by them. I'm very proud of them.</p> <p><a href="https://courageousparentsnetwork.org/videos/im-inspired-by-them-im-very-proud-of-them/">https://courageousparentsnetwork.org/videos/im-inspired-by-them-im-very-proud-of-them/</a></p> <p>Description: A grandmother of a little girl who died from Gaucher Type 2 talks about her pride in her daughter and son-in-law after their daughter's death. "They're capable. They get up in the morning."</p> <p>Transcript:  <b>Melissa:</b> I'm inspired by them. I'm very proud of them. I'm very happy that they are so capable, even though they might be somewhat fragile at the moment. They are still willing to get up every day and to put on their</p>

	<p>clothes and do the things they need to do, and work through the things that are difficult for them to do. That they are so able to express what they are feeling. Steve doesn't do a lot of talking. But when he does, it usually has meaning. Right. Sarah talks. She tells you what's going on with her and it's perfectly clear. You don't have to guess and worry and say - did she mean that or did she mean that. If I ask her this, is that going to make her mad if I do this. It's very clear how she's feeling.</p>
--	--