Sarah and Steve Shaw

Sarah and Steve, parents of Emerson who had Gaucher Type 2. Emerson died at age 16 months.

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TITLE: *The Diagnostic Odyssey: it never occurred to me that it would be fatal*.

https://courageousparentsnetwork.org/videos/the-diagnostic-odyssey-it-never-occurred-to-me-that-it-would-be-fatal/

Description: The parents of a little girl recount their journey from their daughter's healthy first few months, to intuiting something wasn't right (delays, symptoms), to ruling out other diseases, to the devastating diagnosis.

Transcript:
Sarah: So for five months she was always ahead of the curve in everything she did. And we were in this baby group and everyone there had a baby at the same age. And we would go every week. And everyone put their babies on the floor in a circle, you know, first all laying on their backs because they're all, what, eight weeks old at the time?

Steve: Yeah, yeah.

Sarah: And Emerson was the first one that could roll over and the first one that could lay on her stomach on her hands. So we went and -- remember that time when you -- Steve walked in and put her on her stomach and everyone was like, aww, and they were all like don't do that, no one likes --

Steve: We'd been practicing, Emerson and I.

Sarah: I had taken her to her sixth month check up in Seattle. And at that point she had gone from the -- I think it was like the 98th percentile in height and weight to the, maybe 78th or something. It was a pretty big drop. And she was also -- she didn't want to put weight on her legs anymore if you held her up.

And she also was doing a thing that I've since met other parents whose kids have Gaucher that -- or had Gaucher that have said they did this too. She was doing this thing where she would arch her back in a strange way. And at the time her pediatrician checked her out and didn't see anything else. And so he had said, you know, at six months she is starting to eat solid food, she's starting to do different things, you know, he didn't seem that concerned or any red flags. So we just went on our way.

She was about seven months old then -- that she wasn't really doing what the other babies were doing. And she wasn't so far behind that it was shocking, but she was on the lower end when she had always been kind of ahead of the curve. And so I was getting concerned not that there was anything seriously wrong, but just starting to feel like something felt off. And, you know, everyone around me would say, oh, she's fine, she's fine, like, babies grow at their own pace and she's fine.

But then it was at Halloween, we came to the cape, and that was the first time one of her eyes had started turning in. And then her clothes seemed loose. So we had thought maybe she has just grown taller and so, you know, she's going to get fat and thin. And then we measured her and she hadn't grown at all since her six month checkup. And then I think that's when we got kind of freaked out that something was wrong, but still didn't think it was anything life threatening, just -- you know, you don't want anything to be wrong with your baby.

Initially I called the pediatrician's office and said, you know, I'm a little concerned about her development. And they said, oh, you know, just come in at nine months. I think they probably get lots of calls from new parents about everything.

So then I hung up the phone and then I was thinking, you know, I'm really, really concerned. So I called again and said, you know, I have to have someone see her, I'm really concerned. So she went to her new pediatrician. She was so worried right when she examined her because she was smaller than she should have been. She wasn't putting weight on her feet.

And then when she felt -- and she was thin. And then when she felt Emerson's abdomen, she felt what she thought at the time was a mass. And it was really her spleen and liver that were very enlarged.

The first thing they did was -- I think the ultrasound.

Steve: Yeah.

Sarah: And the ultrasound tech -- I don't know that she was supposed to tell us this, but she told us it wasn't a mass, that it was her spleen and liver. And so to us, we thought, oh, she has mono or something.

Steve: Yeah, yeah.

Sarah: You know, like, we just didn't -- so to us that was like the biggest relief ever was that it wasn't a mass. So we had this moment of like -- even

	though it wasn't confirmed and we knew we had to wait till it was confirmed, we had a moment of like, oh, okay, everything is going to be okay. And then we were there for about five days and through that time had a lot of testing. So then the oncologist wanted to do a bone marrow biopsy to check for some other potential blood cancers and things. And then that came back negative. So then when she said potentially leukemia. We had looked up what that meant and we were again so, so upset. Then that came back negative and we were so relieved because we were like, oh, great, okay, so she doesn't have cancer. And we just had never heard of a storage disorder. So when they started talking about it potentially being a storage disorder, I was actually at first, pretty relieved. **Steve**: Yeah. **Sarah**: Because I thought, oh, that doesn't sound so bad, an enlarged spleen, an enlarged liver and thinking she'll take some medicine. And we didn't know what that meant. But they had seen on the bone marrow biopsy what they thought were Gaucher cells. And the geneticist was the one that saw it. And they sent the samples out to the Mayo Clinic. So then we had to go home. I don't know how long it was. **Steve**: It was two weeks. **Sarah**: Two weeks? **Steve**: It was two weeks because towards the end of the two weeks I emailed the doctor again and said, look, you know, I know that Mayo Clinic is very busy, but is there any way we can find out, I mean, it's been two weeks. And at that point -- I'm a data hound, so I had already been reading all the literature. I knew what Gaucher was, I knew what the different -- you know, I knew -- not what the prognosis for what Emerson would be, but -- Gaucher is a pretty wide range. And so I had some idea that it can be really, really bad or not so bad. At that point I thought it could be not so bad. **Sarah**: And I decided at that point that until -- I'm usually -- I usually need to know everything and I need to look everything up. But I decided that until we knew for sure I didn't want to research anything. So we didn't talk at all about the research you had done. **Steve**: Yeah.

	Sarah: Because I had looked up something and came across -- early on come across a blog. And it was by a woman whose child had Niemann–Pick. And I started reading it and I was like I just couldn't go there. And I didn't even know what Gaucher was. And then when she was diagnosed, the geneticist called us into her office and she gave us the diagnosis. And I didn't really know what it meant, but you did. **Steve**: Yeah. I did, but at that time again there is a range and -- so at that time we hadn't met a doctor who had a lot of in-depth experience specifically with Gaucher. And at that point I still believed that there was probably a range and it was still possible that there was going to be a positive outcome. **Sarah**: Well, because if it's Type I Gaucher, there is no neurologic involvement. So with enzyme replacement you can have good results, you know, as far as a longer life span and, you know, -- it's less severe. And then so because we knew she did have neurologic involvement though, that's when I finally did some research. And it was pretty awful what I found and we -- it never occurred to me that whatever she had, that it would be fatal or that there wouldn't be anything we could do.
2	TITLE: *The doctor was very gentle and also clear that there was no treatment at this time.* https://courageousparentsnetwork.org/videos/the-doctor-was-very-gentle-and-also-clear-that-there-was-no-treatment-at-this-time/ Description: Parents of a little girl diagnosed with Gaucher Type 2 talk about how their doctor confirmed she had the most aggressive type and gently, patiently, and honestly prepared them for what their path would be in the absence of a cure on the horizon. The parents appreciated his honesty. Transcript: **Sarah**: And then we had the final testing done to actually identify the mutations. And from there he would be able to say, yes, it's definitely Type II or it's definitely the most severe. But even just from his clinical observations at that first visit, he said that he was pretty much positive that she had the most severe, fast progressing form of the disease. **Steve**: Generally when they diagnose, the younger they diagnose, the worse the prognosis. **Sarah**: That's what he told us. **Steve**: Yeah, generally.

	Sarah: You know, and I think there is such a wide range and I've met people now that do have -- or have or had children with Gaucher and there is such a wide range of prognosis. But he pretty much at that visit, I would say, confirmed that she would -- that she wouldn't live to be three, he didn't think. **Steve**: We started prepping us kind of for what our path was going to be. **Sarah**: And he did start talking -- and I have to -- I was very -- he was wonderful. He was so thorough and so -- like, he was very, like, clear and didn't sugarcoat anything, but he was very warm and supportive and took a lot of time with us. **Sarah**: But he was also very clear that there was no treatment or care at this time. So then we asked him about, you know, are there clinical trials, are there -- there must be something happening. And he was very -- like, he was -- I guess he was, well, like gentle, but clear that while there are some trials and studies and stuff going on, he didn't feel that the science was at a place that it would benefit Emerson and that he -- we could, you know, obviously do what we wanted, but we would put her through a lot and he was very clear that it wasn't at a point where it would benefit her. **Steve**: Yeah. There was no cure on the horizon and there wouldn't be in time for her and if she lived to be the long, you know, a three. **Sarah**: And so I think that was -- I appreciated that.
3	TITLE: *We came to the realization that this is the path we're walking and there is nothing to be done about that.* https://courageousparentsnetwork.org/videos/we-came-to-the-realization-that-this-is-the-path-were-walking-and-there-is-nothing-to-be-done-about-that/ Description: Parents of a little girl diagnosed with fatal Gaucher Type 2 talk about how impossible it seemed that there was nothing to be done to cure their daughter but, with time and digging for information, came to accept the fact that the science just wasn't there. Transcript: **Sarah**: I think we both definitely couldn't believe that there was nothing, like, yeah, how is it possible. You know, I would always say things like we can put people in outer space, we can do all the -- you know, and I know it's not related, but we do can all these things and there is just nothing. You

	know, and it's just -- it seems like, you know, talk to someone else. We talked about -- we think about all the different genes and all the different things in your body and just this one teeny tiny thing isn't right and we can't do anything about it, you know, or -- and so Steve was -- I trusted that he had done a lot of research and studies. And my sister-in-law is a physician and she was looking at things and she's very thorough -- for me I felt like there was enough people that were like, we're going to figure out if there is anything. And our doctor was very open to, like, if we e-mailed him, he wrote back to us. And I think you sent him a few studies that you found to be, like, what about these. He's like, if you come across anything, please run it by me because who knows. And so -- and I think the -- so I had that moment of not being able to believe that there is nothing we could do. But someone and I don't know how this happened, I kind of accepted it pretty early that that was a fact. **Steve**: Yeah. **Sarah**: And I don't -- I don't know why or how. **Steve**: And for me, I mean, I'm not a biologist, but I'm a scientist. So for me I was pretty comfortable with the idea that, you know, that he was being honest with us that this is where the research is right now. And so, you know, and we -- and I did when I did run -- I tried not to take advantage of his willingness to look through stuff because I knew he was an expert and had dealt with this specific syndrome, you know, for many years and so we did send him a few things. But I think his demeanor and my comfort with just where the science was I think -- and thankfully I think we both came to the realization that not accepting of it, but knowing that this is the -- this is it, this is the path we're walking on and that's not -- there is not anything we can do about that.
4	TITLE: *No heroics. Focus on quality of life*. https://courageousparentsnetwork.org/videos/the-best-i-could-do-as-a-parent-is-give-her-the-best-time-i-could-in-the-time-that-we-had/ Description: The dad of an infant diagnosed with Gaucher Type 2 shares that he knew he wasn't going to be the parent who focused on a cure in her lifetime -- it is such a rare disease, that moves so fast, and there wasn't a cure on the horizon. Quality of Life was the goal. Transcript: **Steve**: I think for me I never had that point where I felt like I was going to be the parent who pushed for the cure because -- and I think because we

	have a lot of medical folks around us in our family and that we come in contact with a lot. And again, I'm not a biologist, but I'm a scientist and so I think for me I never had that because it was -- it's such a rare disease and the funding and people and time required to really do something about that is so massive. And there are many common diseases that there is a lot of money and a lot of publicity around, and a lot of people working on it, and a lot of funding for, that still don't have a cure. And I think for me that was kind of my reality check. There are stories where, you know, there is this, you know, miraculous discovery, but I think there is so much background of those miraculous discoveries, so much prior work that's not ever highlighted in those stories. And I think that those kinds of discoveries for something that's so rare, I just -- I don't think that it's -- I didn't find it very probable. And so that was never -- that was never a feeling for me. I just -- for me, my biggest thing was that the best thing I can do as a parent is give her the very, very best life that I can in the time that we have. **Sarah**: Yeah. And I think when we -- I also didn't really have the moment where I thought we're going to find the thing. And I think partly like Steve said, the time that it would take and the pain and suffering she might go through and the unlikelihood that for her it would be the cure, we just -- yeah, we just wanted her to have the best life.
5	TITLE: *We felt we better step up and show her that she picked the right parents.* https://courageousparentsnetwork.org/videos/we-felt-we-better-step-up-and-show-her-that-she-picked-the-right-parents/ Description: Parents of an infant diagnosed with Gaucher Type 2 reflect on how they focused on being happy with her during her short little life and finding a way to see a bigger picture. Transcript: **Sarah**: Sometimes I'll talk with friends about how during her life, you know, we wanted her to just have a really wonderful life. And we were so focused on that. And it's not like we were being really positive and excited and being fake about it. We really were so happy to be with her. And she was funny and she was just a really, you know, kind of like she was as a little baby. Even when she was sick, she was so just easy and calm and sweet, but also mischievous and funny, you know. And so we really did have a really positive time with her. And then we also, I think, on top of that did have this feeling of like she needs us to be our best selves and she needs us to be focused on what's

	really important. And I think after she died, all those feelings that we didn't feel, a lot of that has started to come up. And so I still don't think we dwell a lot on why us, but we sometimes think like, what the -- you know, like, how is this possible. And I think we also -- we also had a feeling -- we would kind of make up like little narratives as to I guess why this happened and try to -- you know, try to think, you know, is there a bigger picture that we don't know about and there is some reason. And, you know, people talk about like -- someone has a child and, like, oh, that child got so lucky to have you as parents. And we kind of felt like -- I don't know even know how to describe it, we kind of felt like she picked us. And so I feel kind of like there was a part of us that felt like she picked us and so we better step up and show that she picked the right people.
6	TITLE: "I couldn't 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/ 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." Transcript: **Melissa:** 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 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 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. **Sarah:** 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.
7	TITLE: She wants to know what it's going to be like; He doesn't until he gets there. https://courageousparentsnetwork.org/videos/mom-wants-to-know-what-its-going-to-be-like-dad-doesnt-until-he-gets-there/ Description: Parents of an infant with Gaucher Type 2 talk about their different wants regarding knowing the disease progression. Dad focused on the data and science and couldn't read the stories. Mom wanted the stories, the connection to others who had gone before. She would watch CPN videos and then select videos for him to watch too. Transcript: **Steve**: There were other -- I saw their stories online. I read -- obviously read tons and tons of things online about Gaucher. And for me going through it, I didn't want to associate with it until I got there, you know, and there were so many things that I was fearful about getting to, like, what happens when we get to this point or what happens when we get to that point. And they were so terrifying to read about. You know, you read them and you can't put yourself there. But then after you go through that part, it's actually much easier in retrospect to read the stories and kind of -- and to -- you don't have the fear because you know that, okay, well, this is what happens and this is what you do and this is what we did. And I'm not going to say that anticipating it

is worse than happening because happening is the worst thing you can imagine. But somehow you adapt to things in a way that you can’t imagine before you go through things. And I think that's probably similar just to normal parenting. You know, you can't know what it's like to be a parent until you're a parent. You also can't know what it's like to have a terminally ill child until you have a terminally ill child, you know.

Sarah: And I think for me though, I think I wanted more connection with other people. I think because, you know, all the fear and the dread. And I think for me when I would talk to other people who had gone through it, there was something about seeing that they were -- they survived. And we did have a friend of a friend introduced us to a couple in California whose son had Gaucher and he had died the year before. But even with them we were just so in it. We've since connected more. And now I think because we're both -- even though they were a year before us, we're both on the same side of it now. And so -- and they reached out and were wonderful and, you know, kind.

But yeah, I don't know, I wanted to connect with other families who had kids going through things, but it wasn’t a specific Gaucher thing. We did have the children's Gaucher research fund. They have a website and they have family stories where people read their child's story. And I did read all of those and I -- because I really -- what I wanted to know was how was this going to progress, what's it going to look like, what can we expect. And no one could really tell us because it varies and it depends on what interventions you -- it can depend on the interventions that you choose or don’t choose. And it can depend on the child and it can depend on so many things. So nobody could really give us any sort of -- any sort of guidelines to how -- like, my big thing was like I wanted to know how was she likely to die.

And our doctor in Boston had said it will likely be respiratory failure. But I just still didn’t know -- I couldn’t picture what does that mean and how do we get from sitting here with her playing with her stuff and still doing new things till like a year or two from now -- he didn’t put like harshly or anything, but -- so I think that -- yeah, and I think the disease is so short, I think there wasn’t a lot of time to process what was happening, get our feet under us with taking care of her and build a community.

Steve: You did read the stories and I didn’t. And I think that's interesting. I was very focused on the data and the clinical progression and what the science said and I couldn’t read the stories. I mean, I just -- I literally could not read them. You know, it was just-- it was too much. And that was -- I figured for me, that we were going to get there anyway and I was just going

	to -- when we got there, that's what we were going to do, you know. And I couldn't think about that beforehand, but you processed it. **Sarah**: I read all the stories on the website. And then I watched the videos on Courageous Parents Network. And I would tell you about the videos. **Steve**: Yeah, yeah. And we did watch a couple of them together. **Sarah**: Well, I would watch some of them and then I'd pick out ones that I made you watch.
8	TITLE: Watching videos helped me put words to things. https://courageousparentsnetwork.org/videos/watching-videos-helps-put-words-to-things/ Description: A father talks about how watching CPN videos of other parents sharing their feelings helped him put words to his own. Transcript: **Steve**: Yeah. So in terms of when Sarah would bring videos to me and kind of how it helped me deal with the dread, I think for me I have to be dragged to kind of sharing my emotions or even feeling my emotions honestly. Like, it's not really my strong suit. **Sarah**: No. **Steve**: No, no, that's true, like, describing or even like describing emotions is not easy for me. Like, I have like good, bad, sad, you know, like I will have like gradations, you know. And so I think that was helpful actually to see other folks kind of put words to things. And just in general I think that they were -- **Sarah**: To hear other people put words to things besides me. **Steve**: Yeah, yes. But yeah, I think that's true for a lot of things, putting words to things is a helpful way to process them, especially for people who aren't intuitively super in touch with their emotions generally speaking.
9	TITLE: The therapist helped us process and translate our actions and feelings. https://courageousparentsnetwork.org/videos/the-therapist-helped-us-process-and-translate-our-actions-and-feelings/

Description: Parents of a child with a life-limiting illness talk about how working with a therapist helped each of them stay on the same page, communicate, understand their different coping styles, and put effort into their marriage in the face of such a difficult challenge. Mom shares one particular tip.

Transcript:
Sarah: We were lucky our pediatrician became just our point person for everything. And she anticipated, I think, a lot of things that we -- and she's not a palliative care specialist, but primary care. But she's just really into it. And she --

Steve: Her personality lends to be -- being able to take that role.

Sarah: Yeah. And I think she anticipated things we might need before we did. And she was the one who -- I don't even know how she brought up, but she was the one that told us -- or she suggested that we go to a therapist.

Steve: Yeah.

Sarah: And she was the one that found us someone that was good, that we really liked working with. And so -- and I think that was really helpful for us just once a week to talk to someone and just kind of make sure we're on the same page. And sometimes things would come up that we hadn't said to each other not because we didn't want to, but it just didn't come up. And so that was helpful.

And so I think I also watched some of the things on the website about, you know, marriage and the relationship or that kind of stuff because that really interested me too because you would read these horrifying statistics about what this kind of situation can do to a relationship statistically. And you know, so I think I was -- we were pretty aware of that and wanting to really make sure we put effort into that piece. And that's not to say that putting effort in means that it goes how you want it to, but we wanted to at least do what we felt we could and for us it worked out.

For me going to the therapist was helpful for a lot of reasons. I'm definitely more of a verbal processor. And so it was just helpful for me on a very basic level just to have a place to go where that's what I was supposed to do, was talk about my feelings, about what was going on, and not because we couldn't talk to friends or whatever, but it was just different.

	But one of the things that our therapist told us and this is a really simple thing, was the only time we really had a real lot of tension was when Steve would get home from work. That was when just -- if there was going to be tension or a fight or anything, that's when it would be. And it would be like I was home all day in this constant state of like -- I shouldn't say constant because we had -- during the day we had lots of fun and Emerson would take some naps, but there was always this stress that -- of what was to come. And so Steve would get home from work at about 5:00. And I don't know if like, I would immediately want you to do something or I would be immediately frustrated by something. So anyway, our therapist had told us that that's usually when people fight. And so she had said like for the first 15 minutes after you get home we shouldn't speak to each other, like, Steve should come in the house, because he'd always want to change his clothes and I'll be like, oh, well, just do this first, you know. So she said for 10 minutes or 15 minutes don't speak, you can say hello, don't say another word. And that really changed things for us. **Steve**: Yeah, that was helpful. And the other thing about having the counselor was that it was -- she was like a neutral observer and she was very good at translating between the two of us. Like, I could say, you know, whatever I'd say or she could interpret my actions and turn them into what I was feeling or kind of like -- kind of just paved the path for just -- yeah, translating between two very different styles of -- we had very similar ways of how we saw our role in Emerson's life and all that stuff.
10	TITLE: Enzyme Replacement Therapy helped. https://courageousparentsnetwork.org/videos/enzyme-replacement-therapy-helped-our-daughter-be-more-comfortable/ Description: Parents of a little girl with Gaucher Type 2 talk about how her doctor explained that ERT couldn't save their daughter but would likely help her be more comfortable with no drawbacks. As quality of life was the goal, they elected ERT to reduce the size of her liver and spleen and the infusions were not a big deal. Transcript: **Sarah**: So the things that we were told that we would likely have to make decisions about were feeding tube, trach, and -- those were the two big ones, the two sort of medical interventions that might be something we would think about down the road. And then the third one was enzyme replacement therapy. And really during our first meeting with the doctor in Boston, he really talked to us a lot about it. And he -- I think he didn't tell

us what we should do, but he definitely went through different interventions and what he thought were some of the benefits and drawbacks. And he felt that enzyme replacement therapy would be beneficial and that other than having to have a surgery to put a port in that it was unlikely that there would be any drawback.

So our big thing was, we wanted to do -- we always kept it open that we could change our minds, that we would discuss this. We wanted to do whatever we could that would improve her quality of life the way that we defined that. And so we decided that enzyme replacement therapy if it would -- because she was so thin and her spleen and liver were so enlarged and she was just -- I think she was pretty uncomfortable. I didn't realize it till later because I would hold her, you know, like on her hip and she would kind of -- you know, she didn’t want to be up against you. And as -- after she had enzyme replacement therapy and her organs were all back to normal size, she was much more cuddly I think. So that's me interpreting.

But so we had decided that we would go ahead with enzyme replacement therapy so that we could address the symptoms that we could address which for her were her liver and spleen, the enzymes can't cross the blood-brain barrier and so they couldn’t fix or even help her neurologic symptoms. But we figured if they would help her with her physical symptoms and make her more comfortable without really causing her any distress or any -- she could still do everything she could do even before that. So we decided for us that made sense.

Steve: And it was important that our doctor supported us in that because in some literature -- and I don't know if that has changed, but some of the literature they don’t -- they actually recommend against enzyme replacement therapy for type II because it doesn’t cross the blood-brain barrier and it doesn’t increase the longevity at all. But it does help with quality of life. So fighting for that and getting that -- and he did that.

Sarah: So then when we started doing the enzyme replacement in Vermont, we were able to just go to our local infusion bay -- well, the hospital there. And it really wasn’t a big deal, you know, because I was home with Emerson all day anyway. And so it was actually for me, kind of nice to go to the infusion bay. We got to know all the nurses. And sometimes my mom would come with me, sometimes my friend Meg would come with me, you know, and Emerson really had a good time there.

I think because she was so young, she wasn’t old enough to be nervous about going to the hospital or be anxious about needles and really they would just -- because she had the port, they would just, you know, put cream on it to numb it and then they would access her port and then we

	would just kind of camp out for the day and the child life people would come in and she watch videos and we could go for walks. And it was kind of, I mean, our weekly kind of outing. It didn't ever feel like a burden. It didn't feel like -- you know, I think it might be different for people -- and I don't know this. And they were just so wonderful there. So she would get her infusion and we'd go on our way. And I think it did -- it made her feel better. She had more energy. And it was supposed to allow her body's metabolism -- her body's metabolism was just, I guess, in overdrive. But it was supposed to help her to gain some weight. And she never gained any weight or grew. She stayed in six to nine month old clothes her whole life. And so it didn't help with that, but it also -- I think had she not had it, she wouldn't have been able to maintain the weight she had. So I -- and that's me speculating, but I believe it allowed her to feel physically more comfortable and maintain the weight that she had. **Steve:** Yeah, oh yeah.
11	TITLE: The doctor explained that not doing a feeding tube isn't the same thing as letting your child be hungry. https://courageousparentsnetwork.org/videos/the-doctor-explained-not-doing-a-feeding-tube-isnt-same-as-letting-your-child-be-hungry/ Description: The parents of an infant with Gaucher Type 2 talk about how the palliative care doctor and nutritionist helped them understand how to think about a feeding tube for their daughter -- not doing a tube didn't mean she was going to suffer or be hungry. The parents find fun ways to concoct high calorie pureed food for her to eat orally, and ultimately never had to make the decision. "You never know what you're going to do until you actually do it. We never had to decide." Transcript: **Sarah**: When we had talked to -- originally talked to the first doctor about a feeding tube, we had decided that we would just wait until it came to that point to decide. We didn't think we wanted to do it because again we knew her life was going to be short and we didn't want to have every intervention. I think though for me I still -- that was a really hard thing to imagine like what does that mean to not do it. And so we did have a palliative care doctor and our pediatrician come up to our house -- I think it was after she had her port put in -- and talk through

all of that stuff again and kind of get to know us. And he was the one that I think that explained in a way -- and I can't remember the word to use that not doing a feeding tube isn't the same thing as letting your child starve to death and that there is ways if she got to the point where she was so weak that she couldn't eat and at that point we didn't want to do a feeding tube that there would be ways to keep her very comfortable and happy. I think I couldn't imagine not doing it because all I could picture was that equals extreme suffering.

And I think talking to him, he gave us at least the idea that we still could decide what we wanted, but it didn't have to equal extreme suffering. But in the end even though Emerson couldn't -- she could only eat pureed foods. And she did have a little bit of trouble swallowing sometimes. She was able to eat on her own throughout her life. And when we talked to her doctor in Boston about her not gaining weight and we just kind of revisited it a little bit. You know, he asked us about what we are feeding her.

And he was saying, you know, even with the feeding tube, I don't know if you can get more calories into her because it was just her body was not able to -- it just was burning through. And so I think that also made us feel -- I don't know, better about -- I don't know what the word is. But she loved to eat. She loved her mashed up bananas. And we would -- Steve would tell about the breakfast that he would make.

Steve: Oh. So we were trying to get a lot of calories into her. So we were researching, you know, all these fats and proteins and things that have tons of calories. And so being the way I am, it was kind of like a game for me, like, how many calories could I -- you know, not forcing into her, but get her to eat readily, you know.

And so these calories -- I mean, these breakfast I made, they had coconut oil was a big one, and so -- because coconut oil doesn't have a big taste and it doesn't make things taste super oily. And so we could get a lot of coconut oil into oatmeal or into mashed up bananas or eggs. She liked eggs if I pureed them. So I'd come up to Sarah in the morning and be like, guess how many calories I got into her this morning, this morning she had like a 500 calorie breakfast.

Sarah: Sometimes it'd be like 700 calories and like -- because he'd be like, I put a teaspoon of this -- and she loved --

Steve: And I would measure, so I knew exactly how many calories were in there.

	Sarah: And Steve would tell me how many calories. And then I would feed her lunch and maybe I'd be like, you know, I'm just going to give her a break and just give her some bananas and, you know, whatever else. And then I'd be like, oh, that wasn't very many calories. But so we were able to keep her getting enough nutrients and calories without a feeding tube. So I don't know what our choice would have been if that had changed before she died. **Steve**: Yeah, I don't know that -- because we didn't have to make the choice. We never -- **Sarah**: It never quite got there. **Steve**: Yeah, we have ideas of what we would do, but with everything you never know what you're going to do until you do it.
12	TITLE: What we were doing was actively protecting her from things that wouldn't be right for her. https://courageousparentsnetwork.org/videos/we-were-actively-protecting-her-from-things-that-wouldnt-be-right-for-her/ Description: The mother of an infant shares how electing NOT to choose medical interventions at first felt like she wasn't actively caring for her child and how palliative care helped her understand that 'doing things' wasn't necessarily protecting her daughter. Reframing to see that sometimes less is more. Transcript: **Sarah**: You know, we had talked to one of her palliative care doctors months before and I was having a really hard time with the idea of, you know, with the disease that she had, type II Gaucher, because there is nothing you can do to try to cure it, it felt like this feeling of -- yeah, we talked, you know, we want to give quality of life, but it felt like this feeling of doing nothing and it felt so -- it went against like every instinct as a parent to have a sick child and just not do anything and then -- so then when you think about interventions to think, well, here is an intervention, what does that -- even though we had talked about it, there was this like instinctual part of me that felt like, well, if I say no to doing something, that just feels so -- it goes again my almost instinct on a primal level, not on a, you know, well thought-out what does this really mean level. And so I think one of the things that I think was one of the most impactful things that our palliative care doctor said to us because we had talked at this point for months with them and they kind of knew what our thoughts

	were and kind of what we wanted. So at one point I talked to him about, you know, I'm feeling like I'm not doing anything. And he had in a really eloquently that I'm not going to quite get, but in the medical field there is lots of things that they can do to keep a body alive and that they can keep doing and doing and doing all kinds of things to keep -- and some of them painful and some of them life changing and whatever, but they can do a lot to keep a physical body going long beyond when it otherwise would. And so he had said, you know, maybe you could think of it as what you're doing is you're actively protecting her from some of the things that could be done that wouldn't be the right things for her. And so I think for me that shifted my thinking a little bit. But instead of saying that sounds like a painful -- or whatever, it's not right for her where she's at right now, kind of the idea of actively protecting her from that was helpful for me to think of it that way.
13	TITLE: Finding Hope https://courageousparentsnetwork.org/videos/finding-hope/ Description: Parents of an infant with Gaucher Type 2 share how they came to see that there really COULD be hope in the face of a fatal diagnosis and the evolution of what they hoped for. "We went from running away from things to running towards things for Emerson." Transcript: **Sarah**: Before all of this happened, I don't think I could have imagined that you could be hopeful when your child has a diagnosis that is a 100 percent of the time fatal and that they're going to die in a very short time. And so I think when we first -- when Emerson had her port put in, the palliative care team came -- just came to visit us. And I don't think we knew who they were really. They were just some friendly people that came and wanted to be really nice to us and talk to us. And they did explain who they were. But we didn't understand at the time really the concept -- the bigger concept of what palliative care is or what a PACT team really does. And so they had asked us about, you know, what our hopes were. And at the time, yeah, it didn't -- it seemed kind of like I was confused by that concept. Did you feel -- **Steve**: Yeah, oh, yeah. I mean, it seems like a weird thing to say, look, what do you hope for. You know, you hope for your kids to grow up and be independent and have great lives, you know. So when you're told that they're going to not live past three, like, yeah, what does hope mean.

	Sarah: Yeah. And I think at that time when we talked with them and looking back it's interesting because we talked that time a lot about hoping that she didn't suffer and hoping that, you know, when she got more and more sick that she didn't have pain. And that was all we could -- that was all we could really think to was that she didn't suffer and she didn't endure painful procedures or painful symptoms. And that was really kind of all we said. And then it was a few weeks later or a month later that we met with another palliative care, with Dr. Macaulay, and Meredith came too, and at that point I think it had sunk in a little bit more. And we had talked more about, like what does it mean, like, what does quality of life mean and what does it mean for her. And I think that we had gotten -- I shouldn't say we've gotten our feet under us because we were still really not, didn't have our feet under us. But we kind of had started to shift our thinking about what her life was going to be and how if this is what it is, what are we going to do in this time and how are we going to do it. And then we also had seen the -- or I had seen and showed you some of the Courageous Parents Network videos. And so when Dr. Macaulay came and asked us again, like that question of like, what do you hope for, I think we had just -- I don't know, we just had a different perspective. I don't know if that's the right word. **Steve**: No, I think that is absolutely the right word. I don't know, because it's -- we had a -- whereas before we had things that our hope was things we were running away from hope was things we wanted to avoid. And then when -- as we kind of got more into it, we had kind of more of a, well, hope, these are the things that we want, these are the things that we're running towards for Emerson. And so I think it was -- yeah, it was putting ourselves kind of more in a like a driver role about what we wanted for her out of this, not what we did want. And I think that was really important for getting -- for helping us through it, was coming up with: what do we want for her.
14	TITLE: Our pediatrician was the key that held everything to together for us https://courageousparentsnetwork.org/videos/our-pediatrician-was-the-key-that-held-everything-together-for-us/ Description: Parents of an infant with Gaucher Type 2 talk about the pivotal role their daughter's primary care pediatrician played in coordinating her care at the hospital and just checking in as a safe place and extra set of eyes and ears. Transcript:

Steve: Well, I think our pediatrician was a -- Dr. Monahan was a -- Meredith was really -- was the key that held everything together for us because from the point of diagnosis to the point of Emerson's death, she was involved. And I think -- I've heard since then, that a lot of times once there is this diagnosis that the pediatrician will often step out because that's not really what they do. And I think Meredith really jumped in from the second things happened, she was there, throughout helping us navigate the medical community. And we -- you know, we have medical focus in our family, so we kind of had a sense of how things would work. But you're so overwhelmed and you're so in it that you don't have -- you can't pull back and see the big picture and you don't have the knowledge of just how the institutions work and who -- what doctor, you know, what's an attending versus a fellow or all those stuff, you know.

Sarah: Yeah.

Steve: And I think Meredith was able to get us to the right people at the right time and introduce us to doctors and kind of direct things as kind of a big picture support person really.

Sarah: Yeah. And she was, I mean, behind the scenes with everything. You know, if Emerson -- at one point she was just, you know, having these fevers and we never really figured out what it was. I think it might have been pneumonia, but it was -- and she would be the first person I would call. And then by the time we ended up having to go -- be admitted to hospital, by the time we got there, she would have already talked to everyone at the hospital and have it all coordinated so that we weren't getting there and explaining what's going on and then trying to figure out who needs to be where.

And she would usually come to the hospital too and physically be there. You know, and whenever there might be a specialist involved, like, we went to the pulmonologist and the neurologist just to get sort of baseline stuff. And she would coordinate all that and contact them, so by the time we got there, they already knew -- I mean, they could read the chart anyway, but she would personally communicate. And I think for me even just like sort of the emotional support, so you know, we lived in a fairly rural place. And I often felt like I was really isolated, I mean, even just physically sometimes.

And so I think we went maybe every other week or every week, we had a doctor's appointment, and it was really just a check in. And you know, there would be sort of height and weight and Meredith would listen to her and look at her and ask if anything is different. But it was also kind of -- became kind of a lifeline for me. Like, once a week or once every other

	week I knew I got to go there and just connect because otherwise, you know, if there wasn't something going on, we weren't necessarily going to see a doctor. You know, I go to the infusion bay. Unless something was happening, we weren't going to see a doctor. And even though there wasn't, you know, going to be a cure, it still felt -- it felt safe to have a doctor look at her. And even just sometimes, you know, to talk about what's going on or to feel like you're just connecting with someone who kind of is on the inside. And so I think for me that was big too, is just knowing that we're going to check in every week or every other week.
15	TITLE: Our pediatrician provided stability. https://courageousparentsnetwork.org/videos/our-pediatrician-provided-stability/ Description: Parents of an infant with Gaucher Type 2 talk about the role their daughter's primary care pediatrician played as the one constant, the primary relationship that carried all the way through beyond the specialists, including after their daughter's death. Transcript: **Steve**: I think she also -- she provides stability -- provided stability because, you know, as things progress in a hospital, you see different doctors, different specialists are going to come in, now your needs are different, so you have a different team that comes in. And Meredith provided that stability that kind of comfort from day one through Emerson's death. And she's -- I mean, everyone else came and went due to what their specialty was or what -- you know, what Emerson was going through. And I think having that person that it felt like you had built a relationship with over a period of time. And that was really important because it was someone that you could trust, it was someone that could translate the medical jargon if it was too much at that time. And you know, I feel like we're pretty smart people, but it's a -- **Sarah**: It's hard. **Steve**: It's a complicated system and you're super overwhelmed and there is a lot happening and it's -- you don't -- you're not a medical person yourself. So even under the best of circumstances, you know, it can be really complicated and confusing, if you're not used to it, and having someone who could step back and we could ask stupid questions to, you

	know, or just providing that trusting relationship from the point of diagnosis through to the point of death and then even afterwards.
16	TITLE: 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/ Description: This video is about how most of this grandmother's attention went to her daughter, not her granddaughter. Transcript: **Melissa:** 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. 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. 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.
17	TITLE: My concern was for them as a couple. https://courageousparentsnetwork.org/videos/my-concern-was-for-them-as-a-couple/ 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. Transcript: **Melissa**: 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. **Sarah:** You didn't take over. **Melissa:** No, no--- That's what I tried to do and make sure that they 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.
18	TITLE: 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/ 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 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. **Sarah**: 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. 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. **Melissa**: I think so. **Sarah**: But I think that, that was really helpful.
19	TITLE: I find her in things. Sometimes it hits out of the blue. https://courageousparentsnetwork.org/videos/i-find-her-in-things-sometimes-it-hits-out-of-the-blue/ Description: A bereaved father shares some of the little moments when he sees and feels his daughter and the challenge of being hit by the grief unexpectedly. Transcript: **Steve**: How we're experiencing the grief and the bereavement now, I think we -- I don't know who told us this, but somebody said that, you know, that you start to find them in things and they start to show up in things. That's the part where that I'm in right now is that I do find her in things or I see her in things. We have this -- we have wind chimes on our front porch. And I don't know if you said this or who said this, but we think -- you know, when they go off and I still say, oh, hi, bug, you know -- **Sarah**: We called her bug. **Steve**: Yeah, right. And -- **Sarah**: Because sometimes it's not even that windy.

	Steve: Yeah, yeah, no, this came out of nowhere, so things like that I think. I don't even know what I'm trying to say. I think we see her in things. And I think I'm at a point where things hit me really unexpectedly. Things that will make me emotional that are not even -- like, commercials, you know, silly things. Like, things that you're -- they just have some sort of emotional tug to it and all of a sudden I'm thinking about Emerson and it really hits me out of the blue a lot.
20	TITLE**:** When she was alive, we invited people in. We are learning how to help people connect with us again. https://courageousparentsnetwork.org/videos/when-she-was-alive-we-invited-people-in-we-are-learning-how-to-help-people-connect-with-us-again/ Description: Bereaved parents talk about how when their daughter was alive, their home was warm and they actively invited people in to share the good times, to share in her life; and now that she is gone, they are figuring out how to reach out to invite people in again. They talk about their evolution in understanding their friends' reactions since their daughter died. "The hard thing about bereavement is that you have to help others figure out how to be with you." Transcript: **Sarah**: When she was sick, I have this sort of little -- I think I love to make up these, like, images and stories around things. But I kind of picture like if we were in this tiny like one room cabin, but there is -- like a terrible storm outside, but in that little space we lived in such a small little space that was really cozy and warm and it was really easy to invite people in because we really were having a lot of good times and we really were completely invested in, like, this is her life. So we really -- I feel like I invited people in a lot. And it felt like -- in some ways we had something to offer like, come in to our warm little place and, you know, have a cup of tea, you know, whatever. And in some ways after she died for a long time I felt just like -- almost like we were outside that and we're just out in the storm. And so I think it's harder to -- been harder for me to, like, invite people there because it doesn't feel like -- like, when she was sick, of course, we were -- had all this sadness and sort of dread about future things and all these things. But it still felt like a place where I could invite people in and feel good about that. And I feel like after she died it was really hard for me to kind of invite people in because it just felt so -- just cold and dark. **Steve**: And like we have nothing to offer, like, you know --

Sarah: Except sadness.

Steve: Except sadness. And you know, others can only absorb so much of that before you start to scare them.

Sarah: We've had some good friends though.

I feel like I'm getting better at like inviting people in and kind of -- I think people don't know what to say. I think they do the best they can. And I think early on if it wasn't the right thing it was really upsetting to me and now I think I'm better at accepting whatever people have to give us is what they have to give. And then maybe they, you know, some of our friends have really expressed that they want us to tell them what's helpful and what's not. And so I think just recognizing that more has been helpful and feeling less alone in it.

Steve: Yeah, yeah, I think. I mean, the hard thing about the bereavement period is that you have to accept that you have to help other people. Part of you feels like everyone should be able to help us, you know, I'm the one who is grieving. But you have to get -- I think, I don't know, I feel like I have to get to a point where I could realize that they're there, but you have to help them with that first part because nobody knows how to navigate that because no one has ever done that. Most have never done that before. And so once you're willing to help them, they're willing to show up and be there. And some people it comes really naturally and can do without that, and those people are, you know, evolved souls or what, you know.

Sarah: Who knows?

Steve: Who knows? But other people aren't there. And, you know, honestly, I probably wouldn't have been there, you know. And so being -- accepting that I'm not sure that I could have done that has made it easier for me to figure out ways to help other people through that.

Sarah: And I think also for me like when Emerson was sick we had so much support coming from every direction. And it felt like people were just so involved. And then after she died, it felt like that kind of fell off. But when I'm kind of looking at it a little further out, I think part of it was that when she was sick, we were actively inviting people in. And we were actively, you know, writing on a CaringBridge site, writing like blog posts and we were sending things out. And, you know, we would -- we were just very actively kind of telling people how to navigate this and what we needed and how we were doing and where we're at.

	And then after she died I think that's also a harder thing for people because when she was alive even people who might have had a really hard time with what was actually happening, they could still say, oh, I saw this little hat and it was so cute, so I bought it for her. You know, so they could still connect with us and ignore the -- what was really happening if they needed to. And then after she died, that becomes harder to do. But I also do think there is a piece of it where in some ways I just couldn't guide people at that point. And so I think that now we're getting a little bit to a point where we can kind of help people in if we want to.
21	TITLE: I'm inspired by them. I'm very proud of them. https://courageousparentsnetwork.org/videos/im-inspired-by-them-im-very-proud-of-them/ 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." Transcript: **Melissa:** 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 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.
22	TITLE: Now I have deep conversations about the burdens people carry. https://courageousparentsnetwork.org/videos/now-i-have-deep-conversations-about-the-burdens-people-carry/ Description: A bereaved father shares how his daughter's death from Gaucher Type 2 has led him to hear other people's struggles and burdens and to open up about his own. "I feel I owe it to my daughter to tell people about her, to let people know she was here. And to then help people move past it." Transcript: **Steve**: I think her legacy is I've had a lot more -- lot deeper conversations and a lot more conversations about -- one thing that's always struck me once Emerson was diagnosed and once we started out with her being terminally ill or that now that she's died, people open up to you when they find out kind of what your burden or what you're carrying in life, you hear

	a lot more what other people -- the burdens other people carry that I think has been really interesting. So people ask if I have kids all the time, you know, and that's -- **Sarah**: That's like the question. **Steve**: That's a question. **Sarah**: What do you do and do you have kids? **Steve**: I mean, not as much for guys as for women, but I definitely get at conferences and things all the time. And I always say that, yes, I have a daughter, but she passed away or something like that. And -- but then I try to be really good -- it's a really heavy thing to open up to somebody about. So I try to be really good at saying it because I feel like for me I owe that to her to mention her until a lot of people know that, yes, she was here. But then helping those people move pass that because some people are, like I said, better at it than others and -- but I think people need to get better at death, honestly, like, talking about death and accepting death.
23	TITLE: We are learning to be patient. We are building slowly. https://courageousparentsnetwork.org/videos/we-are-learning-to-be-patient-rebuilding-slowly/ Description: Bereaved parents share their current struggle as they find their way and their daughter's legacy. "We have to make sure we're stable and helping ourselves. We need to know where we are before we can do anything." Transcript: **Sarah**: I think it's one of those things where like when she was alive, I felt like I had such a clear sense of purpose and such a clear -- everything just that we did, I didn't -- for whatever reason I was able to just feel like very definite and very clear and very purposeful. And then since she's -- and I always sort of had sort of faith and like a bigger picture and I think since she's died I've lost a little bit of that. And so I feel like -- I don't know, I guess being patient that we are kind of building her legacy, but that it doesn't have to be today and it doesn't have to be, you know, this major palliative care centre to -- whatever next year. You know, like it's something that we're building slowly just kind of like Steve was saying through our sort of day-to-day interactions and just allowing that to happen and not be impatient with it. **Steve**: It's like the first responder thing. You know, you can't help anybody else until you make sure that you're stable and that you've helped

	yourself. So I think that's part of we're kind of -- I'm a little bit more, okay, let's do it, let's do it, let's do it. And I think that I've learned patience and learned that we need to be in a good place and we need to know where we are before we can start doing that, I think.
24	TITLE: Now I can have the long view towards finding a treatment or cure. https://courageousparentsnetwork.org/videos/now-i-can-have-the-long-view-towards-finding-a-treatment-or-cure/ Description: The mom of an infant diagnosed with Gaucher Type 2 reflects on how she focused on quality of life during her daughter's short time. But now that her daughter has died, she can look out towards the long road to a cure. Transcript: **Sarah**: During her life I wasn't -- you know, I did some research about Gaucher and did learn a fair bit about the disease, kind of I knew what I needed to know. There is actually not a ton on type II. If you get -- if you just do sort of a Google search, you get information about Gaucher, type II Gaucher is sort of -- it's a little bit of a side note because it's the most rare and it's fatal early and all that. But I was so focused on giving her a really good life. And so it's interesting because I feel like since Emerson has died I've got really interested in Gaucher and the idea of there need -- we need to find a cure, there needs to be treatments. And it's 2017 now and how can this be. And I think that maybe it is -- and I haven't thought about it this way till you said that, having the idea of it being sort of the long view and now I can have the long view. And when she was here, I couldn't have that long view and put a 100 percent into her life while she was here. So there has been a little bit of a shift for me. And I now I don't know that I still had the moment where I'm going to be the hero, they make a movie about who makes the discovery, but I have much more of a desire and a impulse and a sort of hunger for like -- for we need to do this and this can't be how it is in this day and age. And so that's been a shift since she died for me.
25	TITLE: I would keep it together until I talked to Mom. Then I'd fall apart. https://courageousparentsnetwork.org/videos/i-would-keep-it-together-until-i-talked-to-mom-then-id-fall-apart/ Description: The mother of a little girl with Gaucher Type 2 talks about how she would only fall apart when she talked to her mother -- where she

	could be most vulnerable. "You were always the first person I wanted to talk to but the person I couldn't talk to if I needed to keep it together" Transcript: **Sarah**: Sometimes when something happened, I could hold it together and I could do what I needed to do until I talked to her. Then that's when I would fall apart. So I think there were some situations where in the car after the eye doctor, where I just wanted to fall apart. It was nice that my mom was there so I could fall apart. But then there were times where I felt like I needed to really hold it together and I can't do that if I call her. So then, I think you called like a day later, when we were still in the hospital. She was like --- you didn't call me. I think sometimes her support was so important but then I was in this high --- I needed to just act. It was almost like I couldn't talk to anyone. I couldn't; I just had to have tunnel vision. So it's interesting that you're always the first person I wanted to call but also the one person I couldn't talk to if I had no option to fall apart at that point. **Melissa:** That makes perfect sense to me too. That makes perfect sense to me too. As an adult, when I knew I would fall apart, I would not call my father because the minute I heard his voice or saw his face, that was it. You know that was it.
26	TITLE: I think the hardest part is after she's gone. https://courageousparentsnetwork.org/videos/i-think-the-hardest-part-is-after-shes-gone/ Description: The Grandmother of a little girl who died from Gaucher Type 2 shares how challenging it has been to miss her as much as they have and how family wants to help but doesn't know how. Transcript: **Melissa:** She was asking me how it was for me when Emerson died. It was awful even though I knew it was coming. Even though I know it was a release, and I know that nothing was going to get better for her. It's still an awful moment. I was happy for her. **Sarah:** Happy for her because her body wasn't working anymore. **Melissa**: That's right. It wasn't working for her. **Sarah**: Her spirit could do what it needed to do without a body that couldn't work.

	Melissa: That's right. Then my brother said to me -- he said something like the worst is over. I said to him - -the worst has just begun. He kind of looked at me and I said the worst is just starting right now. I believe that to be true. **Sarah**: Because I think we always say like even when we were so tired all the time and we knew that she wasn't getting better, when we could see that her body wasn't working for her, we felt really fortunate that all the way through to the very end that she was always very present and her personality. I see videos now and you can see how much physically and motor skills wise she had declined. We didn't really see it because I feel like we were kind of connecting with her spirit. Her spirit was always really strong, but her body wasn't, just wasn't going to work anymore. But even in all of that, we still had her physically with us. I feel like it's been hard to transition to, what does it mean to be her parent, and what does it mean to have her as part of our life without her physically here. I think that's been --- that's hard. **Melissa**: I do think the hardest part is after she's gone. I think that everybody takes a step back. Nobody knows what to say. Then they want to say something. My family describes it as standing like this, we're ready to do something, but we just don't know how to get in there without upsetting things and any progress that's been made.
27	TITLE: "I spoiled my granddaughter!" https://courageousparentsnetwork.org/videos/i-spoiled-my-granddaughter/ 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. Transcript: **Melissa:** I would give her all the stuff I wanted to give her. **Sarah:** 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. **Melissa:** Coca Cola.

	Sarah: She was like --- I gave her soda. I was like what. **Melissa:** She liked it. **Sarah:** 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.
28	TITLE: It put my heart at rest that they don’t have any regrets. https://courageousparentsnetwork.org/videos/i-put-my-heart-at-rest-that-they-dont-have-any-regrets/ Description: A grandmother finds peace after her granddaughter's death in the fact that her daughter and son-in-law have no regrets about the decisions they made for their daughter and the life they gave her. Translation: **Melissa:** One of the things that she said that made me feel the best was that --- this is not true of all people who have lost children, was that she and Steve honestly didn’t have any of that feeling of we wish we had done this. We should have done that. I don’t know why we didn’t do this. I told you I wanted to do that. Why didn’t we take her here? There was none of that should have, would have, could have, why didn’t we. There was none of that. **Sarah:** We still don’t. **Melissa:** Which really put my --- that put my heart at rest for them. You see if my heart is at rest for them, it’s all good.
	A mother’s testimonial: CPN