

April 2022

Lower Third

Matt and Myra

Parents of Havi and Kaia.

Kaia is 21 months old and big sister Havi died at age 2 from infantile Tay-Sachs disease.

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| 1 | <p>Title: <i>Becoming parents for the first time: Expanding the Love Bubble</i> Link: https://youtu.be/SoB_9AXFv_w</p> <p>Description: Matt and Myra, parents to Havi and Kaia talk about becoming parents for the first time. They look back on all of the emotions that came with the birth of their first daughter Havi and the way it changed their lives.</p> <p>Transcript:</p> <p>Matt: I'm Matt Goldstein, Havi's dad and Kaia's dad and Myra's husband –</p> <p>Myra: I'm Myra Sack, Havi and Kaia's mom.</p> <p>Myra: When I think of Havi I think of beautiful, otherworldly, and warmth.</p> <p>Matt: I think of wisdom, I think of giggling laughter, and I think of love from all sides. Love coming out from her, love being poured into her, [00:03:00:01] just the best kind of love.</p> <p>Myra: Becoming parents and becoming Hav's parents was totally transformational. I think we operated in a space before -- we were -- some of our friends were having children and Matt's sister had a daughter, so we had a niece, but a lot of our world was just the two of us or our closest friends. We loved our life and our marriage. And we were told that parenthood was going to change everything, elevate everything. But I don't think I fully appreciated that obviously until Havi was on my chest at the hospital. Then there was a lot of stuff about parenting Havi that was hard and exhausting and she just totally consumed our world in a really full way.</p> <p>Matt: Yeah. Hav made us parents in such a profound way. I remember after she was born feeling so excited and so proud of her. And I was in the elevator going down to get some food for Myra and I and I ran into a nurse that I had worked with during residency years before, and she was like "what are you doing here?" I was like, "oh my god, I just had our first child, Havi, she's so beautiful, let me show you photos..." and we missed several stops on the elevator because I was so excited. I felt like she was the most beautiful child that had ever been born</p> |
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and she was so strong. And I was also a little scared I think bringing her home. The first day was just a little terrifying. She was like this little precious –

Myra: We didn't have the car seat setup.

Matt: Yeah, the car seat wasn't set up and we forgot to validate the ticket, the parking ticket, and it was a little chaotic, but that was an amazing, truly life-changing few days. And I remember somebody told us, I think this was before Hav was born that you have this love bubble and -- is that right?

Myra: I think so.

Matt: That you have this -- you exist in this love bubble and you feel like there's no room for anyone else in that love bubble, which I felt was so much our marriage up to that point and that it grows a little bit and you find more space in that bubble for this new being, and yeah, that totally happened.

Myra: Forgot about the love bubble.

Matt: Yeah.

2

Title: *The diagnostic odyssey to Tay-Sachs*

Link: <https://youtu.be/y31WZaSSCTc>

Description: Matt and Myra, parents of Havi and Kaia discuss Havi's first year and the steps they took when they began to realize that her development wasn't progressing in all the ways they expected at her 12-month appointment with her pediatrician.

Transcript:

Matt: Our diagnostic odyssey to Hav's diagnosis probably started sometime around when she was 10 or 11 months old. In hindsight, we started to notice that she was having a harder time doing things and wasn't maybe making as much progress as we thought, but we didn't have anything to compare to. She was our first and she was amazing. She was so strong and so sweet and in hindsight, all these things that she did, given her diagnosis, were just remarkable. I'm in awe.

But it came to our head at her 12-month appointment with her pediatrician. And we marched in there that day not really worried about too much, to be honest. And she went through her exam and asked us a bunch of questions and said that she was a little bit concerned about a few things that Hav wasn't doing. She wasn't pulling up to stand, she wasn't babbling very much, she hadn't said mama or dada at that point. And she reassured us that this is really common, developmental delay is a thing that is seen a lot in pediatrics and they're great resources for it with early intervention and lots of other supportive services. And she made a referral to neurology and to orthopedics and to early intervention, which we started all with vigor. That was in September of 2019. And we

proceeded to put Hav through the most rigorous early intervention, two a day, PT, OT playgroup, poor thing, and she just took it all, did it all without really complaining or crying or fussing ever. And we saw neurology, we saw orthopedics. They both I think were so taken by her beauty and her energy and –

Myra: Presence.

Matt: Yeah, the presence of her, of her whole being that they both said that they thought she would be fine, you know? They see tons of kids with life-limiting illnesses and severe disabilities and Hav was not one of them. And so we continued through the fall with this really intensive program. And it was right around Thanksgiving that Hav really wasn't making a whole lot of progress. There were days when we clung on to little things that she had done that we thought maybe she was making some advancements.

Around Thanksgiving, we ended up going to see another pediatric neurologist who is a developmental specialist and she spent about an hour with us, did a really thorough exam, and told us at the end of that exam that Hav had Cerebral Palsy, which was devastating. She referred us to neurogenetics because Hav's birth story was tremendously uncomplicated and very normal and we ended up seeing neurogenetics the next week after that visit. He sat down on the floor with Hav, and I unzipped my jacket, and Hav startled and he asked about that. My said, oh, she has been startling for a while but our pediatrician told us it was sensitive hearing and that a lot of kids have it. He sort of noted it and continued with his exam, which was hard for us to watch because she was not doing so many of the things. Then he asked if we had been screened for Tay-Sachs and we almost laughed at him at that point and said, oh, yeah, Myra was a carrier and I wasn't, and he noted that as well.

Then he recommended that we get some additional genetic blood testing and Hav have some additional tests run and have an MRI to get some imaging of the brain. The day after the MRI, actually the afternoon of the MRI, I went back to his office to pick up some blood tubes for us to have blood samples drawn. And I checked in at the front desk and the nurse paged him and he came out to the front and he said, "can you come back into my office for a minute," which I knew at that moment was a bad sign. And he sat me down in the chair and pulled up the MRI results on his computer screen and pointed to these very classical findings of Tay-Sachs disease and the rest was a little bit of a blur. I don't really remember leaving. But I got back in the car. My sister-in-law was waiting in the car and drove me back home. I came into the house and My was on the phone in our bedroom and I told her what the doctor had said and she screamed... she screamed and said: "she is going to die." We got the confirmatory blood tests the next day. And yeah, we were shattered, our whole world was shattered.

3

Title: *Dropping the illusion of control: Shifting from progress to love and play*
Link: https://youtu.be/_HGBS0ULNuU

Description: Matt and Myra, parents to Havi and Kaia, talk about how Havi's diagnosis of Tay-Sachs allowed them to change their perspective on Havi's life from one focused on making progress and hitting milestones to one where they could focus on just being with their daughter.

Transcript:

Myra: there is a moment in which the previous world, the one where you can control things, the one where you operate not in a world of anachronistic loss or trauma is one where you do whatever it takes because you think that you can control the result, and that's the approach that we took with Havi because she was our daughter. And those months where she was doing double sessions of physical therapy and occupational therapy and struggling through basic exercises and not making progress I remember we would call each other on the car rides from an appointment to work and check in, and those conversations were heart wrenching. She had made a quarter of an inch of progress it seemed on a pull up and then once the diagnosis, the fatal diagnosis settled in, there was a relief in the approach that we took. We could just be with our daughter and play with her and not turn the living room into an exercise room or study her every move as it related to whether she was using her left or her right hand when she was eating and there was power in that for us. If we could get any time back, our only regret would be, half of her life, the first year where we didn't -- we couldn't just operate in that play and love space because we were so consumed by control and --

Matt: Progress.

Myra:-- and progress, yeah. And for -- we were programmed that way. The two of us as sort of type A athletes too, particularly as it relates to what you can do physically, you know, if you just keep at it. So --

Matt: Yeah, even the term early intervention, it's early and intervene, it was this thing of driving toward the next set of milestones and seeing all the right specialists and getting all the right physical supports or equipment or clothing or whatever it was, and it was torture for her, it was torture. The fact we put her through that -- I don't regret much, obviously, but that just feels like it was so cruel. The one that really gets me is the occupational therapist suggested these braces for her legs to help her stand and we had her fitted for them and then drove out to some office somewhere to have them -- once they were done to have them show us how to put them on. She hated it. It was so uncomfortable and awkward. And it just -- and we used them once for half a day and then she was diagnosed with Tay-Sachs and they sat in the corner of the room, and every time I saw them I wanted to just blow them into a million pieces.

4

Title: *Evolving as parents: from feeling shocked and vulnerable to trusting intuitions about what our child wants*

Link:<https://youtu.be/3mwfeVOGi3E>

Description; Matt and Myra, parents to Havi and Kaia talk about transitioning from relying on the reassurance provided by the medical system that gave them clear steps as to what was next before her diagnosis, to focusing on what Havi was telling them she wanted once they knew she had Tay-Sachs.

Transcript:

Matt: How do you know how much to do or what to do and more so, especially at this -- for us the developmental delay diagnosis at the time was devastating. It was incomprehensible. We had this beautiful, perfect angel child who was just full of light and love and all of a sudden something was wrong. It didn't make any sense. Like there was no -- there was a complicated birth or there was no reason why that should have happened. It was incomprehensible. And we at that moment were so -- we were so vulnerable that the medical system, this whole ramp-up system, here's everything we can do full-court press. It was incredibly reassuring and seemed like, oh yeah, okay. Well, if we do all these things then it'll be okay. That's like how we've operated our whole life. And I think it was a conversation with you, Blyth, and Charlie after Hav's diagnosis when you talked about listening to Cameron and that really changed, I think, how we approached Hav. And all of a sudden with a little bit of quiet and a little bit of paying attention it was so clear what she wanted. It was so crystal clear. And she never spoke a word but she made it so easy to understand what was best for her. And I think that's something we really lost sight of early that she was telling us what she wanted the whole time.

Myra: I think what we heard Hav wanting was to be in someone's arms or on someone's lap who loved her, who she felt could make her comfortable. She wanted to be at home. She loved her room, loved our room, loved the kitchen. Havi loved to eat. And she loved anything with blueberries. She loved pastries. So as she -- as her disease progressed and she couldn't eat solid food, we turned everything into a delicious smoothie that was more like a pastry puff in a smoothie. Hav loved the sun and the water, so we got her to the ocean and to beautiful places as much as we could, which is both the devastating and very real aspect of living with a child who has a fatal diagnosis because there really were no interventions that she loved, that she wanted, that she was telling us, so we could just follow her lead and take her to the best blueberry pancakes and the best Pacific Ocean view and that was a gift when we learned to listen to that.

5

Title: *Finding the way forward: "Giving her the life she was telling us she wanted in a condensed period of time."*

Link: <https://youtu.be/Bz7grJs4xqs>

Description: Matt and Myra, parents to Havi and Kaia talk about the moment after Havi's diagnosis of Tay-Sachs that they decided they were going to focus on celebrating Havi. They share their idea to give her as many Birthday's as possible with a weekly 'Shabbirthday' that was a mix of celebration and ritual

Transcript:

Myra: So once we learned that Havi had Tay-Sachs we sought counsel from various people in our community, one of whom was a rabbi, and we spent time, the two of us, talking about how we were going to exist now. And we decided in a conversation that we had, between the two of us, that we were going to celebrate Havi, that we were going to -- that she wasn't going to have many birthdays, but we were going to -- so we were going to condense the amount of time between a typical annual birthday to a weekly birthday that we called -- we thought it was brilliant. We were going to call them Shabirthdays because it was a combination of Shabbat, which happens on a Friday, and a birthday. And we walked into this synagogue to meet a rabbi to share the news about Havi and to talk about our new approach and the rabbi said to us, I don't think that's a good idea because what happens when Havi is not here anymore, how are you going to exist in Fridays and observe the Sabbath. And it didn't sit well. It was sort of like the Walt Whitman quote, I think, when your soul was insulted, ignore it. I think we both had that sort of initial reaction. And we got in the car after that session with the rabbi and sort of looked at each other and said, that's bullshit. We're going to celebrate the shit out of her and so that was -- that became our approach. Our care goals just became how to give her the life that she was telling us she wanted in a condensed period of time. So Shabirthdays included family and friends, always challah because it was the only food that she crawled for. She was a carb girl I guess and then cakes and balloons and music and then always an element of poetry or some sort of mechanism to get it feeling, because we weren't operating in a world of joyful celebrations and we knew that. We weren't trying to pretend that we were. So it was sort of this mix of celebration and ritual and gathering I think that became really the way we lived with her. And we -- so we got 57 of them. And I'm glad we didn't listen to the rabbi. And I love rabbis. Awesome respect, with respect.

6

Title: *Havi's posse just showed up, and it was amazing.*

Link: https://youtu.be/_nyEkWqaOsQ

Description: Matt and Myra, parents of Havi and Kaia, talk about how their circle rallied around them immediately after Havi was diagnosed with Tay-Sachs and showed up for them without a second thought.

Transcript:

Matt: Havi's posse originated completely spontaneously. I feel like after Hav's diagnosis, I don't even remember but all of a sudden everyone was here. Everyone was just here all of a sudden. They all got on their little bad phones and coordinated and just showed up. And I think that is so characteristic -- as we have deeply come to appreciate, that is so characteristic of this group of people, of this family, which is unbelievable. And I think the thing that Jacob said to you that you showed me the other day that he said something like I'm not changing my life to do this. This is my life. And that's how they are. This was it. It wasn't - there was never even a question or a discussion. We never had to ask for

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| | <p>anything. They just showed up. It's like they had been given the instructions, the most perfect instructions by someone. It was amazing.</p> |
| <p>7</p> | <p>Title: <i>Finding support for just the three of us: People who gave us language, validation, permission</i> Link: https://youtu.be/5zEGoQfxvfQ</p> <p>Description: Matt and Myra, parents of Havi and Kaia, talk about how having a circle that reinforced and validated their instincts meant they felt empowered and encouraged to keep Havi at the center of their decisions.</p> <p>Transcript: Myra: I think we learned to bring people along and protect Havi's bubble and follow her lead and ask for what we needed and be directive about what we didn't by consulting people we really trusted. We were fortunate to have Blyth, you, and Charlie nearby, guiding us at really critical moments, validating for us that these were our decisions and that anyone who didn't see Havi as the number one agenda item or priority wasn't the right person or people to be in the space. And so, we used that kind of principle as a way to guide how we chose to invite people or not into the space. I think we also had access to a wonderful therapist who, again, gave us language and validation around what was our right and what belonged to us and that we were -- to act out of love and not fear. And I think just constantly feeling our belief systems and instincts were being reinforced and not minimized or colonized was really empowering for us and allowed us to just keep Havi right at the center and everything else fell away. And we were living through a global pandemic and racial turmoil and all the injustice and uncertainty that anyone could imagine and yet it was the first time in our life where it was about the three of us, and that was such a gift that that you and Charlie gave us and that Dr. Joe gave us and that our family gave us. But I think so often grieving people are not empowered to make those kinds of decisions because the signals they're getting from the outside world are different. They're ones that encourage you to hide or shrink and we just could expand and that was -- that's probably the greatest gift that Hav gave us I think.</p> |
| <p>8</p> | <p>Title: <i>Work: We had to explicitly educate and coach our bosses and colleagues</i> Link: https://youtu.be/lunSmdX9LZE</p> <p>Description: Matt and Myra, parents of Havi and Kaia, talk about how they chose to keep Havi present in every aspect of their lives, including work. They found that taking steps to educate their colleagues and bosses on how they needed support ended up feeling empowering and allowed them to share both the painful and beautiful parts of their experience.</p> <p>Transcript: Myra: We coached our bosses and our colleagues. We continued to work and so we knew we had to educate the people around us because they're not educated about how to talk about and support people like us, people who are living with a dying two-year old. So we were really explicit actually. We wrote emails about</p> |

what felt good and what was appropriate to say and what wasn't appropriate to say. We fully integrated Havi's being into how we showed up. So we wore purple because that was Havi's color. We had pictures of her behind us, sometimes we had her in our lap. We talked about her and showed others that you could integrate someone who was beautiful and sacred and also dying into your life in a way that wasn't scary and we got real power from that. And I think the beautiful thing was that our colleagues and bosses followed our lead and for the most part were just so incredibly supportive and present and still continue to be that way.

I think they were that way because as humans we're naturally inclined to rise to the occasion. We want to be good, we want to be generous, but we're so afraid and we're most afraid of dying or of losing someone that we love. So when that fear takes over, obviously, the biological response is to fight or freeze and so that's often what comes out. And I think with the tools people can do it.

Matt: I think especially during Hav's life, like not hiding her, not hiding the disease, not hiding the pain of her losing all these milestones and bringing people along in that journey to see both how agonizing it was and to experience how agonizing it was, and to experience the beauty and the fullness that came with that.

9

Title: *Bereavement: Outside people are afraid of feeling bad. "The ideal response is to lean in and recognize the grief and anguish."*

Link: <https://www.youtube.com/watch?v=9TPAO0UKxN8>

Description: Matt and Myra, parents of Havi and Kaia, discuss what it felt like after Havi passed when the world seemed to be moving on while they were experiencing intense grief. Matt explores the ideal situation in which people would understand that grief may change how it shows up, but doesn't ever go away. Myra speaks to a hope there will be a more community based approach to understanding grief so that both sides are educated in the experience of the other.

Transcript:

Matt: I think after Hav died that was harder for a lot of people, at least I felt that way that there was a moment or a period where people moved on more, and I think expected us to move on to snap back to normal, to be resilient, which is a term I sort of hate because we're forever changed and life is not going to be the same. It's never going to go back that way. And I think after Hav died after some period of time colleagues and bosses were struggling with that, didn't know how to come to that at all.

I think people are afraid of feeling bad. They're afraid of things that could bring them down. I had a conversation with my boss before I left my job after Hav died. It was maybe six months after she had died. And my boss told me that when I was in the office sometimes that my energy was low, and that I was

bringing people down, and they didn't know how to be around me, and that that was really hard for them. And I was like incredulous, hard for them? are you kidding me? I never get a minute, I never get to hold my daughter ever again and she died six months ago. This is raw. This is raw, raw, raw. And you're telling me that my behavior is making people feel badly in the office or feel down or they don't know how to behave, that's like such a joke. It's so cruel.

And I think that the better response or maybe the ideal response is to lean into that to recognize that grief and anguish and agony and the longing that we have for the people that we've lost is not something that goes away ever. It changes and the color of it changes and the shape of it changes and how it shows up in our lives change, but it never goes away. We don't move past it. And having compassion or recognition or leaning into that in an empathetic way is that's how it should be and it makes us better when we do that, makes life fuller and richer and you see both sides. We're not just focused on one wavelength of existing and a happy state.

Myra: The approach could look much more community oriented. I think an approach could be one in which where people feel like they have an ecosystem of different resources and that would require each pocket to really understand loss and grief and get educated. And I also think that there's also educating grieving people. I remember a conversation we had with Dr. Joe, where we were talking about this feeling that the world was moving on and we weren't, and she described the curve of traumatic loss where when you experience a traumatic loss the pain actually gets a lot more intense before you get strong enough to hold it. So your arc curve is like this and the rest of the world hasn't experienced our traumatic loss, so, of course, their curve is like this. And when I can come to other people and other situations and environments and see in an interaction those curves then all of a sudden their behaviors are less hurtful because I understand the foundation of them. And that's just really helpful.

10

Title: *Writing as healing, during her life and in bereavement: "It forced us to be with our Grief ... And now it's a portal to her."*

Link: <https://youtu.be/fhpJwL7aZFM>

Description: Matt and Myra, parents of Havi and Kaia, talk about how writing to Havi every week became a vehicle for their close community of friends and family to get to know Havi as much as possible in her lifetime. Since her passing, writing to Havi has become a portal to her and a space where they both feel close to her.

Transcript

Myra: So we decided to write to Havi every week and share it with our close community of friends and family, and we did that because we wanted people to know Havi and we thought we were going to have a lifetime for our friends and family to know her, but we didn't. So we had to accelerate that and condense it. And practically speaking, it was COVID and so we couldn't -- people couldn't

come in and out of her life easily. So we wanted to share her adventures and her personality and her beauty with everyone. So in that way it was a vehicle for people to know Havi. So we shared whatever felt important from the week in her life. And from that perspective, all of a sudden it felt like Havi was a part of a world that was bigger than us and I think that's what you want as a parent to know that that your child exists beyond you and that they're loved beyond you and seen. So I think in that way it was so helpful.

And then also it forced us to be with our grief and capital G grief, the pain and the joy and the devastation and the hope all in one passage. And what that did was just allow us to know what we were feeling and experiencing, and it was so healthy because we weren't surprised by hard moments and hard feelings because we were processing them on paper and together. The way we did it was one of us was the lead writer and then the other was the editor. So it also was a way for us to check in with each other. Sometimes Matt would write something and I would have no idea that that was a hard moment or a beautiful moment in his mind. So I think it brought us closer in that way.

Matt: That was beautifully said. I think it was also a way for us to talk to Hav. And in addition to the CaringBridge, My has been writing in a journal to her every day, which is amazing. And that's a way of us when she was here and now still being able to talk to her and tell her what's going on and tell her what we're thinking and that's been really powerful. And I don't do it as much now as My does, but in those moments when I feel her or there's something that reminds me of something we did being able to go to that space and know that or feel like that's my portal to her, that she's reading it somewhere or hearing it somewhere that's good.

11

Title: *Preparing for her End of Life as a Couple: A series of frank and open discussions about the most difficult thing*

Link: <https://youtu.be/tmUPqj5-zC4>

Description: Matt and Myra, parents to Havi and Kaia, talk about what it felt like to discuss Havi's end-of-life and what brought them to their decision not to bury her.

Transcript:

Matt: At some point we I think somewhat prompted by a conversation with our therapist, Dr. Joe, started talking about her end of life and what that would look like and what preparations we would undertake and thinking about that and exploring that. And I, for some reason, had decided that I wanted to wrap her in my tallit, which is the prayer shawl that you start to wear during a bar mitzvah and then you wear whenever you're praying. And I don't know why that popped into my head, but it sort of felt like something that I wanted. And I said that to My and she was like, what? No, we're not going to wrap her in your tallit. What is that? No. And I was like so taken aback because I thought it was this like pure and romantic thing in my head and she was like "absolutely not. No fucking way

we're going to do that.” And I was shocked. But I think that led to a series and was part of or in some ways an entree into a series of really frank open discussions about the most difficult thing, which is how do you bury your daughter who died and what does that look like? So –

Myra: We chose not to bury her. So that was our way.

Matt: Yeah, I think we both felt like we wanted her close. We wanted her remains close by us for however long. And I don't know there was something about the idea of putting her in a cemetery somewhere by herself, that didn't feel right. She's ours and I think that made sense.

Myra: Well, neither option feels particularly good, but –

Matt: No, I mean honestly.

12

Title: *For the little sister Kaia: “We’re going to make Havi as big a part of her life as we can.”*

<https://youtu.be/J1T9QedWgIo>

Matt and Myra, parents of Havi and Kaia, talk about how they keep Havi present for their second daughter Kaia who was just six months old when Havi passed, as well as how to teach Kaia about the incredible presence Havi has in their lives as she gets older.

Transcript:

Matt: Kaia was about six months old when Havi died. When Hav was diagnosed Myra was 11 weeks pregnant with Kaia. So we got Hav’s diagnosis in the morning and that afternoon we were in high risk OB getting chorionic villus sampling to test Kaia to see whether she was affected or not and fortunately she wasn't. She is a carrier. She has my mutation. And she got six beautiful months with Hav and thousands of photos of them together. We talk about Hav a lot, every day, all the time, and there are photos of her everywhere in the house. And we talk about her to Kaia a lot. And I think that now Kaia knows that there is someone, knows that this presence of Hav is an important person in her life, but she's confused too. And every night when we put her down for bed the last couple of weeks she has been running through the list of people we know to say goodnight to. She says “dada, mama, JJ, booboo, bababa...” and sometimes we will help and say Lulu, Miley. She says “Lulu, Miley, Titi...” and at the very end and we say “and most importantly Hav” and she gets real quiet. And you can see she's thinking, and she knows that there's someone there, but she hasn't quite gotten her hands around it yet I don't think.

But I think that we're going to make Hav as big a part of her life as we can. And I think we're going to make Hav as big a part of our life as we can and as we have done and we will continue to do. So I don't think Kaia is going to have any choice about whether she knows her or understands her power and her beauty and her

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| | <p>wisdom. But it is something that we've been grappling with a little bit and especially recently just how this person, Hav, has been such an incredible force in our lives and is such an incredible presence in our lives and that we're going to have to teach that to Kaia. She's not going to necessarily know that on her own in the way that she would have had she'd grown up next to her as she should have. So that story will continue to get written I guess.</p> |
| <p>13</p> | <p>Title: <i>The little sister's footsteps bring joy ... and tears</i> Link: https://youtu.be/raDmA0xo4Eg</p> <p>Description: Matt and Myra, parents of Havi and Kaia, talk about how they are experiencing “grief through Kaia’s existence” and learning to allow themselves to experience the full range of emotion that comes with each milestone moment where they feel joy and are simultaneously reminded of their loss.</p> <p>Transcript: Myra: Kaia is doing things that Havi never did. And there are some moments where it's overwhelming and in the same 32nd moment where I watch Kaia easily climb up and stand on her stool for dinner. I'm overjoyed, and amazed, and proud. I am also devastated and back into early grief, acute grief. And that can happen in literally 30 seconds. And I think the capacity to go from laughter and joy to sorrow and tears and then back fluidly is what we're learning how to do so that we can experience all of it without compromising Kaia’s childhood, of course, and also not forgetting or minimizing Havi’s presence. But grief through Kaia’s existence is definitely like the phase that we are in. At least that's how I feel.</p> <p>Matt: Yeah, yeah. I think footsteps are the thing recently that's been really hitting me hard. I dreamed of the day with Hav that I would come home from work and walk up the front steps and she would come running down the hall. I dreamed that I wanted it so badly and now Kaia does that and I hear her footsteps during the day when I'm on the phone and it's the most amazing thing and the most painful thing. And those two just they are and we don't have the choice, but man, it makes those footsteps sound so good. So yeah, it's hard.</p> |
| | <p>Title: <i>Message to parents: Trust your intuition.</i> <i>Message to clinicians: Listen to what the child and parents want and do whatever you can to make that happen.</i> Link: https://youtu.be/MTYcJoKQxd4</p> <p>Description: Matt and Myra, parents of Havi and Kaia, share their advice for parents of children with life-limiting illness and the clinicians who interact with those families every day.</p> <p>Transcript: Matt: I would like parents of children with a life-limiting illness to know that they don't have to hide or be afraid that there is so much pain and anguish in what they are experiencing and what is ahead for them, but there is also fullness</p> |

and beauty in that and that those can exist coexist and that there's space for those to coexist. And that the world doesn't really show up in the way that it should and that's really painful and hard, but it's okay not to feel like you have to be a part of that. It's okay to step outside of that and chart your own course.

Myra: Trusting your own instincts and your own soul level or gut level intuitions because they're right for you and your child and your family.

I think that what clinicians could benefit from hearing or knowing or learning is that what they say and the way that they approach families matters a lot and impacts families a lot. And there's power to their words or their silence, and that what it would look like to be there in a way that might feel good is actually not so complicated and that there's -- that the standard doesn't need to be so scarily high or out of reach. And that we appreciate how difficult their jobs are. I can only imagine that role. And I think it's really important that there is education that they embrace that is love based and not fear based because they have power.

Matt: I think that clinicians need to know that they're not always and maybe not, in most cases, really that important of a person in the room. And that what is most important is to figure out what the family and what the patient, what the child, wants and needs and then to do whatever they can to make that happen. And if that means not being part of the medical system and not being in the hospital and not having to come in then that's what they should do, use their power and influence and everything that they know to make that happen in the most seamless way.