

*April, mother of Jackson.  
Jackson had Krabbe Disease.*

1	<p>Title: <i>A diagnosis of Krabbe; and the medical team getting to meet him before his condition progressed.</i></p> <p><a href="https://youtu.be/gf6SzodJIzo">https://youtu.be/gf6SzodJIzo</a></p> <p>Description: Jackson's mom describes the journey to his diagnosis with Krabbe disease (an LSD) at 4 months old, including the moment when the medical team delivered the diagnosis. She is glad so many clinicians were in the room because they got to 'see him in all his perfectness' and establish baseline.</p> <p>Transcript:</p> <p><b>April:</b> I am April Jackson Garcia. And every time you say Jackson's name or Jackson's mom, even given this setting, it just makes me smile. It's always nice to be able to hear the term mom and kind of be able to reflect on that. So I am already in a good spot. Thank you for that. Jackson is my little light.</p> <p>We were super, super blessed that we were going to have a baby boy. He came right on schedule in August of 2015 and life was great. Everything was great as many of the rare disease stories start out. Everything was fine. Then we find out later on, we were so distraught, say that with a smile that we thought maybe he had torticollis or that he was maybe colicky. He had some issues that we were dealing with some muscle spasms. And he had acute regression right around the four month mark. And I think that it was important to pass on to the pediatric team that it wasn't that he wasn't meeting milestones, but he met them and then lost those abilities as far as being able to take a bottle, his feeds, grabbing for things and his motor skills.</p> <p>So we were very, very lucky. We are outside of the Atlanta metro area, and we do have access to being seen at a renowned children's hospital, Children's Healthcare of Atlanta. And when I hear other stories, I didn't even realize that getting to that access could be such a hurdle. Pediatrician spoke to them, explained about the regression. We were told that it would be great to do a follow up with the neurology.</p> <p>And by the time they did the MRI, they were starting to notice in some white matter. They are looking into genetic tests that they can do. And I specifically remember the nurse was trying to put in the code for LSD. And also my kids not on a trip in hallucinogens. So what else is LSD? And that's when I looked at lysosomal storage disorders and started to understand about the genetic condition that they were screening for. I didn't really think much of it. I thought, well, they are super thorough. God bless Joe for thinking that through. I had no idea think about that.</p>
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Everybody remembers D-Day, D-Day for us and the community's diagnosis day. So they -- the hospitalist, they come into our room, and she did say, you know, the doctors want to talk to you. They have some results. Great. Come and talk to me. Well, they want you to come down into this room, they can talk to you. No problem. And I started to pick Jackson up. And she was like, no, it's okay. You can leave him here. No, I haven't live in here for five days just because I like the view. No, it's all right. And I definitely felt that she wasn't hearing my voice and attempting to separate me from him. I thought that she wasn't taking our need to be together seriously. And then she was undermining my choice in thinking that, that I wasn't going to be able to process or handle the information if I was still managing Jackson. But that wasn't her choice to make. So whatever she saw in me that made her think that I didn't appreciate her judgment at that moment. I did tell her that Jackson needed to come with us so they could come down to the room, because at certain point we are not debating anymore. So they did let Jackson come with us.

There is a huge, huge amount of people, because it's a teaching hospital. So every specialty has their team. And it was neuro hospitalists, geneticists. Again, neural hospital and geneticist is there tells about Krabbe for diagnosis, K-R-A-B-B-E. And it is one of the leukodystrophies. And as far as outcome, it's one of the worst, because there are other leukodystrophies that have different onset, different outcome, but this one was the bottom of the barrel.

They gave us a projection of about a year of the amount of time that we could have with him. And I specifically asked them -- remember asking a year from when, you know, is it an year from when you got the scan a year from now? It's a year from birth? I remember asking that they had seen this before. They had said yes. I did ask did it look like this? They had confirmed that. So I definitely, definitely, definitely devastated, said a couple of four letter words.

I was very happy in retrospect that Jackson was in that room, because you don't realize the team of people that are following your child because they don't always even come in the room. And I understand that they don't and there is not anything against that practice. But it was, in retrospect, very important to me that they actually looked at him and saw him as a child. Because at that point, and then not that he wasn't always beautiful to me, but he was still so perfect. It was very, very hard to understand. I just thought I had a child with colic. And he was a fussy eater and had been on a change of schedule since the holidays. And he had no other outwardly way that you could look at him to know that he was going through anything. So I am really glad they have got to see him in all his perfectness. And that would be important to me later on because we will become frequent fliers, and I wanted them to see him how he was enough to just appreciate him, but let's

	<p>acknowledge some changes because you need to have a baseline so you could see what I see in him.</p>
<p>2</p>	<p>Title: <i>A mother's need to get as much information as possible; while the pediatrician may be protecting against too much.</i></p> <p><a href="https://youtu.be/vDWcv5tFwjU">https://youtu.be/vDWcv5tFwjU</a></p> <p>Description: "As a parent, I definitely wanted some action items. I was not okay with go home, and we will follow up with you later. There was zero sense of urgency. As Jackson's mom that was not okay." Jackson's mom describes her quest to get as much info as possible, including about experimental treatments, and her displeasure that insurance and her child's pediatrician were gatekeepers to some of this. There was some tension with the pediatrician. "I asked him if he thought that I was being unrealistic. I said you understand I know that there is not a cure. You understand that I am not putting him through anything that is unnecessary or painful. But knowing all the options helps me contribute to his quality of life."</p> <p>Transcript:</p> <p><b>April:</b> As a parent, I definitely wanted some action items. I was not okay with go home, and we will follow up with you later. There was zero sense of urgency. As Jackson's mom that was not okay. Even if you could have me come into your office and repeat the same information to me after about a week's time for it to sit in, I would at least know the next time that it would be brought up again. The unknown of we will get back with you. There wasn't an urgency. Nothing was going to change. There wasn't any other level of testing or confirmation or secondary anything. That was very, very bad for me.</p> <p>I did do my own research. That's the kind of people that we immediately become. I did find someone who specializes in specifically Krabbe, not just in leukodystrophies. And we did talk with the pediatrician about getting a referral to go there. I didn't like having to get a referral from the pediatrician because I didn't want to have to get someone else's approval to sign off on our need to get more information. I felt like if you are already a part of our team and the information wasn't being provided, then I don't mind you knowing that I am going to get more information, but can you see how you might be a barrier. I didn't want that to be option to be a barrier. But we had to get our insurance to approve it.</p> <p>We traveled to Pittsburgh and got a wealth of information about what equipment to order ahead of time, what the deterioration looks like, what the different stages of the disease are, how do other people manage before they get their G-tube and how it needs a location to go with it, and how they are handling the reflux and whatnot. I had a tribe, and that made the difference. They gave me the providers. They gave me someone who does this all the time, not once a week, not once a month, not just if they get stuck with the</p>

worst of the worst, but that's their full time devotion. And I wanted to be in that lane.

The pediatrician didn't see the value in it, because he was definitely hesitant for us to go back again when we were interested for follow up. And he very directly told me that Jackson was his patient and not me. So he really wasn't there to meet my needs of comfort for understanding what was happening with Jackson, but he was there to manage Jackson's care. And if the visits yielded no different outcome for Jackson, that he wasn't really a supporter of them. And I did tell him that I appreciated him being honest with me. And I asked him if he thought that I was being unrealistic. I said you understand I know that there is not a cure. You understand that I am not putting him through anything that is unnecessary or painful. This is someone who watches the progression in children and can tell me what is going to happen? He said, yes, basically you understand what's going to happen is not going to change what's going to happen. I said, I disagree. I think it changes the value of the time that we have and the way that we attack it. And he said, what do you mean? I said, okay. If Jackson is going to lose his vision and/or his hearing, and I could understand which one may come first, are we going to spend our time on outdoor concerts? Are we going to spend our time on 3D movies, as an example? And if you don't think that that contributes to the quality of what's going on with him, I don't have a better way to explain it to you.

I think his resistance was saying that none of those things would change his clinical outcome. I don't think that he was valuing the quality of his life and not in a cold hearted way. I felt he was a pure clinician. And I want to say if to give -- if I want to give him some benefit of the doubt that he knew that I was worried about the quality of his life. And so maybe he didn't need to take that on as management. But I heard him theoretically saying, and not in a bad way either, just saying, I am really not here just to hold your hand through this to make sure you are okay with what's happening to Jackson. My responsibility is to make sure that Jackson is okay. And I heard a little bit off on that. What I heard he didn't say is and to make sure that you don't overstress him or have him commit to unnecessary testing, to have this happen to him with no improved outcome. Because what the concern was, that I gathered, was going to Pittsburgh, that they were going to be pro stem cell transplant, right? Because you are not going to find a lot of Krabbe kids. You need to get your numbers in. You got to get them going. They want a good outcome. But all outcomes aren't going to be good. Strictly a numbers game.

So the more people that we can see, the more we can build our research, and the more it's going to be better overall. So I think he was concerned that we were going to be a guinea pig even though we are within a good outcome. And I was happy to come back and tell everyone happy, we are not a candidate for stem cell. We never thought we were. But there was zero guidance, because it wasn't thought to be something that needed to be guided.

	<p>The only conversations that came from a clinical standpoint were talking about end of life.</p>
<p>3</p>	<p>Title: <i>Feeling as a PARENT at home vs Speaking as a professional advocate for my son in the hospital</i></p> <p><a href="https://youtu.be/xIjhHx2aCtQ">https://youtu.be/xIjhHx2aCtQ</a></p> <p>Description: "Did you ever not just feel like you are more than one person. I was like Jackson's mom is at home. Jackson's advocate is here [in the hospital]. Jackson's mom is a hot mess, and she has a foul mouth and a quick temper. And Jackson's advocate [with the doctors] is professional, direct and driven. And this is the person that serves him best."</p> <p>Transcript:</p> <p><b>April:</b> She came in and she goes, ah, I am Dr. Johnson. I just learned about Jackson's diagnosis and palliative care, and I have come to talk to you, and I am so sorry. I am so sorry to hear this about your sweet little boy. And I just can't imagine what you are going through. And this is devastating news. And I am just – I am so sorry. I can – it's just a lot for you right now. And what are you feeling and what is happening for you in this moment, and just, you know, we are here for you and just whatnot. And I said, you are very nice, but I don't need sympathy. I appreciate that. That's not what I am actually here for. I am here to learn something from you that I already don't know. I have time to cry on the way home, and it won't be right now. So as much as I appreciate you recognizing my space, that's not where I am right now. I am in go mode. So thank you. And maybe we will just put a pin in that one for later on. That's not where I am. It's not where I am. I need to know you know. I need to know what I don't know. I need to know what you see happening. And I want to make something move.</p> <p>So I -- some version I asked her to walk it back, because I was not ready for the emotions. They are warranted, but it's not someplace I can function in. Did you ever not just feel like you are more than one person. I was like Jackson's mom is at home. Jackson's advocate is here. We are not wanting the same. Jackson's mom is a hot mess, and she has a foul mouth and a quick temper. And Jackson's advocate is professional, direct and driven. And this is the person that serves him best. So this is who you have. Jackson's mom can't come back to the phone right now, right? Because she is not going to help us. She has been put on the back burner</p> <p>You know you are the parent. They know you are the parent. But the moment you only speak and the voice of a parent, I feel that it takes away some of the validity of what you are saying. You try to match energy in a good way. You are talking to me in a professional situation, I am responding in a professional situation. I go home and break down in the car and melt, because I feel like if I do it in front of the doctors they won't be able to talk to me the same way.</p>

	<p>And I don't hold them liable or guilty for that. They are either going to not feel comfortable to give me bad news. They won't think that I will be able to undertake it, or they won't --. They will think that the information that I am giving them is too emotional.</p> <p>So it is very difficult to deal with what's happening and also try to walk it as almost like a professional. You think like almost like this is a case that you have been handled. You are a professional advocate. You are speaking on behalf of the patient. You are working through everything. You are using the terms they use. You are being as reasonable as possible.</p>
4	<p>Title: <i>In the early scary days, with shock of diagnosis, parents don't register the supportive resources they are handed.</i></p> <p><a href="https://youtu.be/tccCt9p4fqM">https://youtu.be/tccCt9p4fqM</a></p> <p>Description: Timing is everything. The mom of a boy diagnosed at 4 months with Krabbe disease describes what types of information parents can handle in the early days with diagnosis: clinical information early, then they build a capacity to think more broadly about finding support. "If they had anyone in the hospital when we were having our longer stays, when we were not in a scary place, but just in a waiting and testing place, I would have loved to have learned more."</p> <p>Transcript:  <b>April:</b> We are listening to all the information that's given to us, and logic as I am talking to you, I got the CPN fire when he was first diagnosed, but I wasn't in a position to do anything. When I was in that mode, I didn't have that information. What -- that would have been the time that I was ready for me and the way that I took on information, it would have been great if it would have been brought up to me again later on. Because then I get discharged from the hospital with a bunch of outdated paperwork. None of it registered with me.</p> <p>Later on, if it could have been like, hey, we realize you are taking him to PT, OT, vision therapy, tactical therapy. There is also this group that you might want to connect with. That would have been great. If I could have also -- if they had anyone in the hospital when we were having our longer stays, when we were not in a scary place, but just in a waiting and testing place I would have loved to have met someone. I have got to know the chaplain, and I have got to know people in palliative care that would come by and see us. And that's why when I would see them again, even if things weren't great they were already known to me. And it felt like somebody more on my side because all their information wasn't strictly clinical driven. It was more about where we were in that moment and what our needs were going forward.</p>
5	<p>Title: <i>During his life, and at his service, I didn't really want to share Jackson a lot with other people.</i></p>

<https://youtu.be/ZCyVKodL5qs>

Description: The mom of a boy who died of Krabbe Disease describes the small team of people she invited to his service: his pharmacist, his PT/OT people . "The people who saw us in our home setting." She grieves the broader community of people he never got to meet but fights the regret and gives herself grace for keeping his world small.

Transcript:

**April:** We had a very nice service for Jackson. I was not able and elected to not have a viewing. Actually still sometimes don't want to even share him. I didn't want to share our videos with him. I just didn't want to. I told my mom I was going to be a little bit selfish. Lot of people wanted to come. I didn't want lot of people to come. His care team came. That meant a lot to me. His pharmacist. You know, those are the people that are, hey, I know he needs his med, and you forgot to call it in, but it's ready. Thank you. You have a million people to worry about. His physical therapist, occupational therapist came.

And then, you know, you don't have little league and you don't have, you know, neighborhood friends. And you are like, wow, these are the people that saw us in our home setting and observed this part of our life. And then it made me -- it did not make me happy, and now it makes me happy. Then it didn't, because I wanted him to have what I thought were traditional encounters in a traditional way. And then sometimes you even see the people that are moved and have these really nice, you know, like fundraisers and, you know, telethons and stuff and all the people they get to share their child, and I don't know -- we were between learning stages and things moved quickly that, that was just not a reality for us. And then also I didn't really want to share Jackson a lot. But -- I don't know, that's just not the way it went for us. I was grateful for the people that we have, but definitely acknowledged the people that didn't get to know.

When we look at the times we had between being a frequent flyer, and I am looking at, you know, did we get in the pool? Did we get to the park? And I am just saying, would he have liked to have other interactions that I didn't push for. You know, everybody came to us. We were building a bubble before building a bubble was cool, because it was easier to manage. And I don't know if I could have got our show on the road a little bit more. That's all. I always felt like it was a risk.

6

Title: *The road to DNR: Only when the situation called for it; timing is everything.*

<https://youtu.be/uwAFtt1K4m4>

Description: The mom of a baby with Krabbe describes the way she considered her decision-making in different emergency situations (related to his breathing), and working with the EMTs. "It was like being in a sadistic game show. Which option do I pick?" As his condition progressed, her decisions changed. (This video is complicated but clear.)

Transcript:

**April:** So our DNR story was -- I liked our -- the hospitalist at our local ER, because we live in outside of Metro Atlanta. Before we go to CHOA, we would have to be EMS into CHOA, right? Because it was an issue. First thing EMS comes, and then we go to our local ER. Love, love, love our local ER hospitalist. And he was always there. The two or three times we had to go we always saw him. He doesn't know my name. He wouldn't know if he ever saw me, but he could tell you all about Jackson. And he would say -- we would talk and have that discussion when it was time.

The first time when he had to be resuscitated in April, he's like, hey, what do you want to do here? What do you think is going on? I was like, oh, you know, I am not sure. Tell me what you see. He's like, well, we know he has this disease. We don't see anything else going on. But it's like his lungs are okay. But I think it has more to do with his apnea. But he was constructive that, you know. I was like, okay. So we can work through that. So we don't want to intubate him, but if you can help us get down the CHOA. He's like, that's fine. I am okay. Let's do that.

But when we went back in August, when it was his birthday, he was like, mom, mom, we got to talk. Okay. What's going on? He has got fluid on his lungs. I was like, okay, but fluid can be resolved. You are telling me he has like regular fluid, like I would get fluid, or he has disease progression fluid that's in a different part of the lung that's never going to get better. He is like, no, he has got regular fluid. He was like, and I remember specifically because he had us over to the side and in my line of sight they are bagging Jackson with Ambu bag, and I was like, I can't -- what my decision. He stepped in front of me said, no, she could do that all day if she needs to. You can make the decision about exactly what you would like to happen. Okay. If he has fluid on his lung did you do an x-ray already? Yes. Is it on both sides? No. Okay. So for some systemic on both sides, and it might be more of a progression. So one side it might be something more viral bacterial and may be able to be treated. So we treated. He might be extubated. It might not be something permanent. I was like -- it was like being on, like, a sadistic game show. You are like, which option do I pick?

So I was trying to run through that to understand what was happening before we would move forward. Okay. Let's -- if we need to intubate him, we are going to intubate him. He was like, okay. That's what you want to do, and that's all right. Do you have a DNR? We do not have a DNR right now. He



	<p>was like, that's fine. You don't have to have a DNR. I just ask him. He was awesome with us.</p> <p>When we had to go into CHOA. We knew we weren't going to have a lot of time left. But we are able to come back home, had to go back in. That was August. We went back in October. And he was not able to hold his numbers. He wasn't giving his oxygen saturation. Did x-ray. There was no fluid this time. He did ask me what I wanted to do. He was bagging Jackson. I said I don't want him to be intubated again. We had a hard time getting him extubated. We had to do several trials -- we do one trial, but then you had to go on high pressure. The mask and that's very -- it's almost -- it's not cruel, but it's not comfortable. So I was like, I don't want to intubate him this time. He was like what do you want to do? I want to take him home. He said, okay, can you at least do me the DNR to transport him home? He said, because I am going to have my team get him home. But they have to have something to cover them in the interim. That you -- you have seen me enough. You are talking to me in a way I understand, deal, deal. That's the only time that we did that. I said I didn't want them to be in trouble, have a liability issue. He agreed for us to get EMS home so we would be able to get there comfortably and quickly. So we could be home with Jackson.</p> <p>He actually called us the next morning. He thought he was going to give us his condolences, and Jackson hung around for a couple more weeks. That was one thing that I did appreciate that rapid response. Hospitalists were helping us. Tell me an unfortunate story that a mom, child passed. The mom brought the child that was deceased in the back of her station wagon to the hospital. I was like, oh, okay. He talked to us about that. We got that find, put it on the refrigerator. He said also, God forbid, you don't want to become a crime scene. They need to know that this is a progression. It has nothing to do with you. I was like, are you serious? Yes, he is serious. Okay. So we had that one.</p> <p>And then I had a little yellow binder. I wanted to be a happy color. I put it together for my husband. I said, if something happens to me and I become catatonic, if I pass out, if I am removed from being myself, I need you to understand what I know so far. And I don't think he would be able to put it into action and didn't expect it to, but I expected a team of people be able to help him understand our wishes. I did have that fear and not from a martyr standpoint, but had specific ideas about how I wanted Jackson to be able to transition comfortably. And if I did lose my mind, I didn't want to come back to reality and realize that something else had taken place.</p>
7	<p>Title: <i>The value of Palliative Care: At first I thought they were the Grim Reaper, but I learned they would always be there for us.</i></p> <p><a href="https://youtu.be/KLPqg7jD7qg">https://youtu.be/KLPqg7jD7qg</a></p>

Description: The mother of an infant with Krabbe disease describes her growing appreciation for the palliative care team and the ways they showed up for her. With them, "You could exhale. ... We could build to comfort and familiarity with them. ... When they came into the room, I didn't have to be On."

Transcript:

**April:** I definitely thought they were the Grim Reaper. I really didn't want to be associated with them. But every time we were in the hospital, they would come by, and they became friends who happen to work in palliative care instead of these palliative care haunts that kept showing up. So I was able to ask them things as an insider who just happened to be one of my friends. And getting to see them before I needed them was really immenseful for me, because even though I didn't have an understanding what palliative care was. I was happy to see someone on the CHOA team who would always be there for us.

The boundaries are horrible. Getting in touch with specialists are horrible. And just having a card and knowing someone actually answered the phone, and that they were never disappointed to see us. It wasn't like you guys are here again. They are just like, oh, hey, Jackson, how is it going? Are you good? And I don't even know if they had to do a lot of things for me, but I knew that they were there. And I think for the clinical team knowing that we were talking to palliative care, and that we were walking through those steps made them feel better. That it was maybe one less thing that they would need to address for they knew exactly who to direct our other questions to, because we were already connected. It helped.

Right. And then I will even say this, in situations where you build more familiarity, and that doesn't usually happen in hospital stays because even they are extended, they are not back to back, right, if we can help it. You are not seeing the same staff and even the physicians that are monitoring the case or managing. They are not client facing all the time. So I can go back to not just bragging on Dr. Johnson and her colleague, Maura. They were the people that I saw more often. And then there was you could kind of exhale. I wasn't on show. I wasn't -- I just be like, yes, yes, I am tired. Yeah. No, I was like, no, I broke down earlier. I am okay. And that would be okay to say that. And it was more the familiarity and the fact that they kept showing up, that we could build to that comfort.

Now, any other provider that we are in a position to see, no matter what their demographic makeup, we could have potentially built that as well. The hospital system is just not designed for that. So the way that palliative care help serve us is I know when they came in the room, I didn't have to be on. And so that was a break for me too. And it was like they were visiting me as

	<p>just me and not me as Jackson's primary caregiver and the point of contact. It was with the familiarity.</p>
<p>8</p>	<p>Title: <i>A mom on deciding this time NOT to treat. "When its disease progression, forward doesn't look the same."</i></p> <p><a href="https://youtu.be/pJXJN7yJks4">https://youtu.be/pJXJN7yJks4</a></p> <p>Description: The mom of a little boy with Krabbe explains her decision-making process in deciding not to treat/intubate her son, when in a previous instance she had decided to treat/intubate. As his condition deteriorated, the questions she asked changed. (An excellent example of parental thinking around decision-making.)</p> <p>Transcript:</p> <p><b>Blyth:</b> Why did you decide, after all the previous hospitalizations, not to hospitalize him when his -- when he was clearly beginning to -- when he was stopping breathing? Why then?</p> <p><b>April:</b> Because before it was something that could be managed. We know if you do an x-ray, and there is fluid on the lungs, specifically, maybe it is on one side, both made me think it was less of a systemic process and more of an infection or virus that he could not fight on his own. So he said, If there is an infection or virus, and he can't fight it on his own, and this being his intubation will give him a chance to recuperate from that, then we can move forward. When it's disease progression, forward doesn't look the same.</p> <p>And we had had that discussion between my husband and I. And I imagined that he agreed with me, or he was just happy to not be leading the discussion. So he is away, I worked out that we would not be able to be selfish and keep him for us. Because that was the thought I did have. And I had asked them -- happy to see the hospitals that have seen us before. And I would ask his nurses too, Jackson is in there, right? Like, you see what I see? How much am I projecting? Because I don't know how to not see every little nuance. And I don't understand if things change. It might not be as obvious to me. And they -- whether truthful or not, they definitely said, no, we see Jackson. I can tell there is different grunts. I can tell he cuts his eyes at me. I understand that he understands where he is right now in a certain way. Okay.</p> <p>Then another hospitalist we had talked about how infants don't do well when they are intubated, and on event they have a hard time with infection. And I said it was a hole in the systems. If his mind is still intact, is intact in a way that is, because there is neurological and that myelin sheath is being deteriorated all the time, okay. And there is nothing to stop and those enzymes to keep them in place from that withering away. If his mind doesn't tack, and he needs help to breathe, we are going to help him breathe. But if his brain is not able to even recognize the signal, not just help getting it through, not just</p>

	<p>a poor connection, you know, putting his lungs through that amount of things. I am not sure if that makes good sense, and not be selfish.</p> <p>I am not going to let him suffer. If he is struggling to breathe, we are going to give him something to make him comfortable. And then make sure he doesn't struggle. Not going to make him struggle. I will say that last time when they said that we were going to -- we told them I want to take him home. I didn't want to intubate him because there was nothing that looked like it could be cured. If it's disease progression, we know we cannot cure that.</p>
9	<p>Title: <i>A quiet end to my son's life</i></p> <p><a href="https://youtu.be/a6aeHZh0IZU">https://youtu.be/a6aeHZh0IZU</a></p> <p>Description: The mom of a baby with Krabbe disease recounts her son's end of life. It was anticipated and peaceful, and yet 'it was a total shock.'</p> <p>Transcript:</p> <p><b>April:</b> Right around Jackson's first birthday we had the whole house decorated. He had a very bad day. His numbers tanked. We ended up back in CHOA. He actually did have to be intubated. He did have some fluid in his lungs. We were successfully extubated on his birthday. There is all kind of stuff they do in hospitals, very, very sweet. And again, I kept thinking this is also real. That means if they have a group that comes and does, like, finger painting for your children or make molds for their hands, that you have a whole bunch of kids up here that are not doing so good either. And I couldn't understand that there was a whole program and a whole little things head up.</p> <p>We did get to go home. We knew things weren't going to be so great for very much longer. Jackson surprised everybody. We had August. We had September. We had a good outing in October. And then mid-October on the 21st he had a really bad day, specifically told my mom, I've seen Jackson lose color. I have seen him lose air, but I actually saw the life drain out of him. And I think he is trying to go home. So we just kind of hovered over him all day. We watched Shark Tank, sit on the couch, and we had him -- poor thing.</p> <p>I always had him on that little tethered vital thing when the baby want to wraps around your toe your finger. And you would think that it was malfunctioning, because they would just doop, doop, doop, and there would be nothing there. You are like can't be nothing, kind of hit it and take a breath and come back. And kids with Krabbe leukodystrophies do that. They can total all the way out, give a minute, come back, and they do that for a long time. And that's part of how the baseline is sometimes. That's what the doctor understood. But one time he cycled in just to come back around, and I was actually shocked. As much as we had had all the conversations. I did the brain bang. I had to sit. I did not have to. I elected to fill out paperwork that whenever Jackson was transitioning home that he would be able to make a</p>

	<p>contribution to help other kids. And I remember filling out the paperwork and holding him and just having this, like, this almost, like, a dark laugh. I don't -- how can I be filling this paperwork and I am holding this child right here, and I am -- and it's just horrible</p>
<p>10</p>	<p>Title: <i>“My race does play a role in my need to strive to be overly on top of information. I want to be taken seriously as Jackson’s advocate.”</i></p> <p><a href="https://youtu.be/ApgP8yxCFe4">https://youtu.be/ApgP8yxCFe4</a></p> <p>Description: A Black mother describes how she felt she had to work harder, strive harder, to be her son's advocate and taken seriously. "If you are someone who you realize that other people may unintentionally marginalize for whatever reason, age, color, sex, weight, accent, all of the above ... It did play a role in my need to strive to be overly on top of my information, and extraordinarily articulate. Because I want to be taken seriously as Jackson's advocate. And it is very, very hard to not just keep the emotions out."</p> <p>Transcript:</p> <p><b>April:</b> No matter how you see yourself or think of yourself, if you are someone who you realize that other people may unintentionally marginalize for whatever reason, age, color, sex, weight, accent, all of the above, right? I will say that it does play a role in my need to strive to be overly on top of my information, and extraordinarily articulate. Because I want to be taken seriously as Jackson's advocate. And it is very, very hard to not just keep the emotions out. Sometimes you are worried about being left out of other conversations or not being seen as approachable, but not being seen as worthy as being a part of the ongoing conversation.</p> <p>So it's a constant understanding that there is a possibility that I may be counted out quicker than I am counted in and have to work to reauthorize myself as part of the conversation every time. So that is just how it is. In situational, you know, it went back and forth about Jackson coming down to the room when it was time for diagnosis. He can stay here, and she was just kind of putting me off. No, the nurses are here. That's not what I said. They can watch him. That's not what I said. I wasn't being heard for whatever reason. The pediatrician did attempt to side with my husband to kind of be like, well, you know, how do you -- what do you think? Why are you looking at him? Is he the primary person? Is he the primary caregiver. Why are you trying to side with him? I will go without both of you. What are you hearing that you are not understanding?</p> <p>So there was of couple of instances where I definitely was being looked over. We will never know the reason. But it does force you to strive to recommit to being attempting to be part of the conversation. And it's hard. And I think there are other instances where people can probably be themselves without being counted out, and not having to rise up to an over-exceeded version of</p>

	<p>what would be needed to be deemed worthy of talking to. So we will never know why, right? But you have to constantly work at it, constantly work at it.</p>
<p>11</p>	<p>Title: <i>A mom on grief in bereavement: "I hope to be myself again."</i></p> <p><a href="https://youtu.be/BWv1owhMRhU">https://youtu.be/BWv1owhMRhU</a></p> <p>Description: A bereaved mother speaks courageously about how she has sought and found support following the death of her son. There are things she did early on -- "I was taking it hour by hour" -- and challenges she gave herself to make sure Krabbe disease didn't take even more from her, such as buying baby presents for friends. "I grant myself grace.... I still want to make Jackson proud, so he will never have a mom that quits. ... If I'm here, it has to count."</p> <p>Transcript:</p> <p><b>Blyth:</b> What have you received in terms of grief support? Where have you found -- have you sought grief support? Have you --</p> <p><b>April:</b> Not under that name. But being able to speak my emotions in the moment in a safe place is definitely something I have had. I am Jackson's godmother, and then my mom nonstop. I had a couple of different things I would try to hit during the days, especially earlier on. I had agreement with myself if I made it through the entire day -- it was just actually just surviving the day, that about the time in the evening when Jackson transferred to heaven that I could definitely have a moment to myself. And I wouldn't push back any emotions that were coming. And those things early on really helped because I was literally, you know, taking an hour by hour, honestly, taking an hour by hour.</p> <p>My personality, I not to say it as a game, but as a challenge. I would tell myself. I did not want Krabbe to take any other thing away from me. So I remember when Jackson transferred to heaven in October, it was about to be like the holiday season. And all the baby's first Christmas stuff was out and it was -- it's just you are in hurt. And then I would force myself to go down that aisle. I was like, I am not losing one. I am not losing one more space to this bad word of a disease. I was like immersion therapy times 10. I am giving them. And I was like, oh, having a baby shower. Like, I am coming. I am giving the best gift. I am going to be in charge of games. I am going to do what I remember that I would do even though it doesn't seem natural to me because I want it to be natural again.</p> <p>So those were things that were helpful to me when it didn't come automatic. I did worry. I was like mom, I kind of liked myself. And I hope to be myself again. I would tell my mom that she would never judge me. She was like, no, you are all right. And hopefully, you will be alright again. But we know it was never a guarantee. I do appreciate currently being someone who enjoys life.</p>

And I know that that was not a small feat. I grant myself grace. I still want to make Jackson proud. So he will never have a mom that quits. He will never have a mom that shies away from things. And I think about if I do something how would I be able to explain it to him in real time? I can't say, Jackson, you can't play with the other kids because mommy doesn't have any other kids. Well, that's not right. No, we play with everyone.

Three years ago the couple next door moved in and had a baby named Jackson.

**Ashley:** Wow.

**April:** And they had the exact same shower theme that we did. I was seriously. So we are very friendly with them. And right before we got on this call he got out of the car and wanted to see Miss April and show me his pirates hat that he made at school. And I am glad I didn't miss that. I don't want to miss any of those things. And it's okay for it to hurt because it comes from a beautiful place. And hurt is a recognition of being here. And so if we have to be here, it has to count. So we continue to work through it like that.

**Ashley:** Oh my God.

**April:** And sometimes I want to lie about how long it has been because it hurts like it's brand new. He looked very much like me. He had curly hair. And I tell God, do not get used to having him to himself. That he is just filling in for me. And I still worry about it. And I know that's not right. But God has a lot to do. I just had one kid and like --. So I was like, listen, I am not doubting you, but it's like only thing I think about.