Michelle Moon

Mother of Alex (age 7) and Julianna. Julianna had a severe form of Charcot-Marie-Tooth disease and died at age 5.

1 TITLE: Julianna's beginning: Charcot-Marie-Tooth disease

https://courageousparentsnetwork.org/videos/juliannas-beginning-charcot-marie-tooth-disease/

Description: In this Zoom interview with CPN, Michelle, mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5, gives an overview of Julianna's life, including the diagnostic odyssey, her hospitalizations, their decision to stay at home with hospice, and her end of life. "That last hospitalization, we were finally introduced to palliative care ... I think everyone kind of knew it was going in that direction, and so they finally offered it to us and it was such a relief finally to be able to talk about these things that were still difficult. But to be able to talk to a medical team about them, about our fears, what we wanted, what may happen and what could be done, that kind of thing."

Transcript:

Michelle: Steve and I got married during my residency. I am a neurologist. He was an Air Force pilot. We had our first son Alex and he was perfectly healthy and we were kind of a normal family tale and then we had Julianna and then for a while we were -- we just had the struggle of a normal family raising two kids under two. Around the time she was turning one, she was not really hitting her motor milestones. Everything else was okay, verbal, cognition but she wasn't pulling up and she was not standing and so we went down that whole pathway. And as a neurologist I kind of knew the things that could be wrong and all of them were scary and so I really tried not to go there just yet because her pediatrician and I, at that first year's checkup, we decided that everything is okay except for the motor. So maybe she is just going to be a late walker or maybe by doing aggressive physical therapy and that kind of thing that Ju would catch up, and so we went that route and it didn't. She made some progress but not a lot and so kind of the older she went -- older she got without doing those things, it got more likely that there was something underlying, causing a neurological issue.

So it's kind of a long story how we got to the diagnosis but at about 18 months I actually figured it out before anyone. We discovered that she had a neuropathy, a really bad neuropathy called Charcot-Marie-Tooth which is actually genetically based one. She had inherited it from my husband and we had no idea that he had anything because he was -- he is perfectly healthy. And it ended up that he had -- he has a very mild case but hers is very severe

because she got an extra gene mutation that made her case very severe. So anyway, around 18 months we had a diagnosis. At that point, she was still fine except for the fact that she couldn't walk and that kind of stuff. And so we continued the aggressive physical therapy and at that point we weren't sure she'd ever walk, but if she didn't then we were determined to kind of make her have the fullest life possible and be independent and that kind of stuff and so that was our goal.

At the same time as a neurologist I knew that with neuromuscular diseases like this, the stuff you worry about is breathing problems and feeding problems. Because if those start then that's what ends up limiting life spans and so we -- I was aware of that from the very beginning. I took her to a pulmonologist; I got her checked out even before she had any issues, that kind of thing. So we found that she had some problems with her breathing already and she needed to use -- she had sleep apnea, that kind of thing. So we treated all that. So we were doing everything we could.

Then shortly after she turned two, she developed a runny nose and by that evening she was having a hard time breathing and she had it and we needing to go to the ICU. It was a long hospitalisation and that's the first time I felt how scary it was that it could go so quickly and that she would need the ICU and need respiratory support. And then from there things just, they kind of snowballed. They -- we -- every time she would go to the hospital, we would try some new treatments, we would try to avoid germs, so we would just do -- we would have more things we'd try to do to keep her lungs healthy but it didn't work.

And so that year that she was three, three was the worst. We ended up in the hospital four times. Every time she went in she got worse. The hospitalizations themselves were hell. She had to have these breathing treatments that were frankly torture. And I mean they were necessary to keep her to get her through but they were awful. And so that year she went from being able to walk a little bit in a walker and take a few steps. And by the end of that year she couldn't even sit up by herself. She was completely dependent on a feeding tube and she also needed to wear a BiPAP which is -- it's a way of helping her breathe. So basically it's a mask on the face. She ended up needing that most of the day. And so it was a very kind of -- very dramatic decline that year.

And so that last hospitalization, we were finally introduced to palliative care and to the palliative medicine team because I had known for, I don't know how long, maybe six months before that, that it was going that way. And I think that's kind of the double edged sword of being a doctor and a mom because I kind of could see some things but I didn't want to believe it and I didn't want to tell anyone because what if I was wrong. I didn't want to scare

them but it is so -- all of that was racing on in my mind and it was really difficult. But that last hospitalisation I think kind of everyone, without even having to say it, I think everyone kind of knew and so they finally offered it to us and it was such a relief finally to be able to talk about these things that were still difficult. But to be able to talk to a medical team about them, about our fears, what we wanted, what may happen and what could be done, that kind of thing.

And so we made the very difficult decision to start hospice and that was fall of 2014, so she had just turned three, and that was around November. And I remember not knowing whether she would make it through the winter because winter is really scary. That's when you get colds and we haven't been able to keep her healthy so far, so I didn't know how long we would have her. And it ended up being much longer than that. We made it through that winter, we made it through another year and so she ended up being in hospice for 18 months which was longer than I could have imagined and it was a really good 18 months.

Yet during that time we still did a lot of medical treatment, almost nothing changed and we did – we were doing all our treatments at home and all the care that we were doing, it's just that the focus changed. And so we thought a lot harder about doing things that were uncomfortable and I think it -- it also allowed us just to kind of focus on her and what she wanted to do and she was a child and she wanted to play. So that's what we did and I think I really -- I think that made a huge difference. She -- if there is such a thing as thriving when you're in hospice, she kind of thrived. And it was -- we had a lot of magical times. I mean at the same time her body was getting weaker, that was undeniable.

And so of course she did end up dying rather suddenly. But I am really, really grateful that we were -- we made that decision and that we had that beautiful time together.

TITLE: A mother who is a doctor reflecting on her discovery of palliative care as an option for her child.

https://courageousparentsnetwork.org/videos/a-mother-who-is-a-doctor-reflecting-on-her-discovery-of-palliative-care-as-an-option-for-her-child/

Description: In this Zoom interview with CPN, Michelle -- mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 -- reflects on how she first thought about palliative care. "If I was offered that early on I could see how it would really upset me because for such a long time we were doing everything medically... and I wouldn't want to think about the worst case scenario... On the other hand if I had known that this kind of standard of care is what we offer for parents and patients -- it's

optional but it's really beneficial, we offer it to everyone -- I think I would have accepted it because I needed to talk to someone about these fears that were keeping me up at night and I had no outlet.

Transcript:

Interviewer: You talked about how you were referred to palliative care when it became clear that it was going in that direction. You know at Courageous Parents Network, we would like to think about palliative care as sort of a gap-filler and an extra layer of support for any child who is living with serious illness.

Michelle: Yeah.

Interviewer: Not necessarily a child who had the prognosis that it's definitely going to end in death.

Michelle: Yeah.

Interviewer: I'm curious whether you know now that once you've had that, well first of all I would love to know what's in the -- palliative conversations looked like? Who were the palliative care people? And whether you think it would have been appropriate for palliative care to have been introduced sooner in her care, if that would have been helpful to you and your husband?

Michelle: Yeah.

Interviewer: If they had been introduced sooner because you are already dealing with extraordinary medical complexity?

Michelle: Right, yeah.

Interviewer: You know the decision to have a feeding tube which probably in her case was a bit of a no-brainer, but certainly around the breathing and you know was there ever any talk which is, and this is part two of the question, was there ever any consideration about a tracheostomy?

Michelle: Yeah, yeah. Yeah, you know it's interesting. I didn't even know what palliative medicine was, being that I am a doctor. I thought of it as well it was she may need hospice and that's when -- well that's when you come in. I didn't know that it's something that you could introduce early on, any time there is -- any time you have a serious diagnosis. So I don't know for a fact, I don't know how robust their services are or were, at that time. I suspect maybe they weren't and maybe that's why it wasn't offered. I honestly did not know that it was an option or what it was. And I think that if I had -- I thought about what my response would be, if I was offered that early and on the one

hand I could see how it would really upset me because I was, for such a long time I was all like -- we're doing everything medically we can. We were just going to -- you know we were going to do everything perfectly and just give me more to do because we will do it. And well you know if it's going to make her be healthy then we'll do it and I wouldn't want to think about the worst case scenario. So part of me, thinks that maybe I would have been scared or maybe even mad if someone had offered that. On the other hand if someone -if I had known that this is kind of standard of care like this is what we offer for parents and families and patients who are going through this or this is just -it's optional but we -- it's really beneficial, we offer it to everyone. I think I would have accepted it because I needed to talk to someone about these fears and well, how -- what I was worried about and what those different scenarios could be because like those were keeping me up at night, and I had no outlet. And so I think I would have -- I think we would have benefited from that early on because those decisions you are asking about I guess on the one hand again, the double-edged sword of being a doctor. Like I was already thinking about those things, so I guess I was ahead of you know like out there for most people or whatever it is, you know how to face this. But some of those things were so scary that it's like you didn't want to think about all even verbalizing it and so yeah it would have been -- it would have been good to have that support earlier on I guess.

Title: A Mom on deciding about a feeding tube for her child

 $\underline{https://courageous parents network.org/videos/a-mom-on-deciding-about-a-feeding-tube-for-her-child/}$

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — shares how the feeding tube intervention was to help Julianna get nutrition but led to medical complications. Julianna went from the G-Tube to the GJ-Tube.

Transcript:

Michelle: The decision about the feeding tube, so that was interesting because she -- we had always worked really, really hard to feed her so she never was underweight. She was -- she was okay that way and she was growing but it was extremely difficult to feed her. Like at one point, it took at least six hours a day to feed her, six hours plus and whenever she got sick like a runny nose, it got much, much harder and then she had to wear the BiPAP all the time and so then we just lost a way to feed her. So we ended up making the decision to do the feeding tube and you know that's a pretty relatively simple procedure. I talked to doctors about it and most people told me that you know parents in our situation that once you get it in and it's working, they kind of regret waiting that long to do it and so you know I felt like it was -- we felt like it definitely needed to be done. It ended up being really not the

case for us. We had a lot of problems with her feeding tube, so we did like a G-tube, so going through the stomach, which is what people usually get. It worked fine in the hospital for that day, as soon as we got home, that thing gave us trouble. For some reason she could not tolerate feeds through the stomach. She -- no matter what we did with the type of feed whatever, she would -- she would retch and she would throw up and it would be unpredictable and that was incredibly dangerous for her because she was at such high risk for aspiration. So that thing actually became a nightmare and it was -- it added a whole other scary layer that we had to deal with and that's what actually led to her hospitalisation and she did throw up and since she aspirated and had pneumonia and she ended up going to hospital again.

Fortunately, they were able to convert that G-tube into a GJ-tube which is putting a wire and going into the small intestine and she tolerated that much better. And so once she got -- we got that in it was fine.

But it was really dicey for a while because we didn't know. If that didn't work we had no way of feeding her.

4 TITLE: Exploring the idea of a Trach: "No one could give me a guarantee that it would extend the quality of her life."

https://courageousparentsnetwork.org/videos/exploring-the-idea-of-a-trach-no-one-could-give-me-a-guarantee-that-it-would-extend-the-quality-of-her-life/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — describes all the reasons they opted not to get a trach for Julianna: her love of talking, the potential complications; the lack of a guarantee; BiPap was working; her condition was progressive.

Transcript:

Michelle: The decision for trach for us, part of it was because of how important it was for her to talk, and verbal communication was so important for her. She -- she was beyond her age -- her years, verbally and she -- I look at -- I listen to videos now, it's like I have like recordings that are like over 30 minutes of her just talking the whole time. This is on BiPAP with really high pressures and like -- I'm thinking like it's hard for a normal person to talk for 30 minutes at a time, you know? And here she was like she did and she did that all the time. It was so important for her to communicate. And she would get upset and she didn't get upset very often but when we couldn't understand her, like sometimes it was hard to understand her, she would get upset. Like tears would flow and so it was so important for her to be understood and communicate that way that the decision to put in a trache

that would limit that and potentially get complications and that kind of thing, it just wasn't -- it just was not the right decision for us. And that was a very difficult decision but it just -- in my -- in our hearts we knew that that wasn't the right path for us.

Interviewer: Did you -- is that a conversation you had with a specialist or with a palliative care person? Like who did you have that conversation or those conversations with?

Michelle: So with my husband, with our family and then like I -- as she was getting sicker and in a hospital, I would have conversations with the pulmonologist about what is -- what would it take to be like -- what is life like with a trach and what are the complications? That kind of thing and so they told me and so I learned a lot more about it than I knew. I guess one of my concerns was before if you have a trach, that I didn't know that if she could even be mobile, if she could leave her room and so I -- we -- I learned that you know there is a -- that she could -- that there is a battery-operated van that she could have and that kind of things. So I learned about that. And they told me -- the pulmonologist told me that some kids with the trach, they are in the hospital every few months or at least every year with a cough -- with an infection. Some of them have to have a lot of airway clearance with the trach and some don't. And there was really no way to tell us if she would be one of those people that had problems or not. No guarantee, basically. There is also no guarantee that having a trach would prolong her life.

Interviewer: Okay.

Michelle: And you -- and she was also pretty stable on her BiPAP unless you know unless she got sick and if she got sick and she had the trach maybe it would make it easier to clear the airway but maybe it wouldn't. Basically no one could give me a guarantee.

Interviewer: Yeah.

Michelle: That could -- and we think that this is going to really help and it will help not even the quality of her life but no one could tell me that this would extend the quantity of her life, no one could say that or had a good chance of doing that. It was very, very that basically they didn't know. And so I took that and certainly with the risk of -- with risk of complications and knowing how important it was for her to communicate verbally and not really that informed a decision. So yeah, we talked to the pulmonologist and then we talked to the palliative care team about that and that's how that went.

Interviewer: And would you -- was there any pressure that you were receiving to get a trach or were people pretty -- well you are in this gray zone

together where everybody is under -- where everybody understood that in the absence of a crystal ball, it became about trade-offs?

Michelle: So the ENT which, I like him, well he seemed a little bit surprised. I think in his term -- in his view that a trach was a pretty simple procedure. I think he said something like, "if it was my kid, I would get a trach." Which I didn't really -- until after that, I didn't really realise that, oh that's -- it was an interesting thing to say in a care conference.

But in previous conversations with him, I honestly don't think he was thinking about the situation because Julianna had a progressive neuromuscular disease, it's not like she had a stenosis or something that could be corrected and that kind of thing. And he even told himself, once he said because he -- when we were talking about trach before, he was saying, "Well it can be -- you can take it out." And then he said, "Well that probably wouldn't happen in this case." And in honesty it wouldn't happen, as long as she was going to get better. So he did say that, but I honestly think he wasn't looking at the whole picture, and he wasn't thinking about the complications that could happen.

TITLE: Palliative Care: I was able to unburden my worries to one person ... and then the care conference allowed us to talk about everything.

https://courageousparentsnetwork.org/videos/palliative-care-i-was-able-to-unburden-my-worries-to-one-person-and-then-the-care-conference-allowed-us-to-talk-about-everything/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — articulates how palliative care helped her specifically. The care conference at the last hospitalization, the conversation about trach and trajectory and hospice.

Transcript:

Michelle: I think for me honestly, it was just the fact that I was able to unburden everything that I had been worried about to one person.

Interviewer: Yeah.

Michelle: And she ended up arranging a care conference, which was really -it was really necessary and it was really good you know our care conference
was huge. There was like, probably 30 people in there. I mean by then we had
been in the hospital many times, everyone knew us but we saw everyone
from our doctors to nurses to social work to all of the therapists, respiratory
therapist and so it was kind of like we all came together finally and could talk
-- talk about things and so that -- that was kind of huge.

Interviewer: What was that conversation like? What we -- what was the focus of the conversation like? And was this the last hospitalisation or one of the earlier ones?

Michelle: Yeah, it was the last hospitalisation. I think that part of that was talking about trach or no trach. Part of it was talking about kind of trajectory and again there was no guarantees. So basically they said -- the pulmonologist said that they had seen kids that -- as long as we could keep her healthy, they could just be stable and even BiPAP dependent and at that time, I had -- found that hard to believe because I had, like we just hadn't been to do that, despite all our efforts. And we talked about hospice, and we talked about the -- we talked about social services and the difficulty I was having -- we were having and getting any kind of help. So we just talked about everything.

TITLE: A Mom reflects on when quality of life bumped into quantity: We asked, "What are we doing?"

https://courageousparentsnetwork.org/videos/a-mom-reflects-on-when-quality-of-life-bumped-into-quantity-we-asked-what-are-we-doing/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — shares the progressive complications that came with Julianna's condition and trade-offs they had to wrestle with.

Transcript:

Interviewer: At the beginning, when you first got the diagnosis and you understood, you were like, "Okay, we'll do everything possible, you can have the best life possible," and it sounds like you know certainly until you realised that it was progressing fairly rapidly downhill, you -- it was about length, right? Like quality of life and length of life. Do you remember a moment or that a feeling where you realised that quantity and quality were no longer concurrent, that quality was going to mean a shorter life span?

Michelle: I mean I thought that every single time she got a respiratory treatment, and those damn hospitalisations. I mean they were honestly, yeah but what she had to go through, I thought that every single time they had to do one of those things, put that tube down her nose.

And that last that year, when -- you know when she was three and she -- we were in the hospital four times. Like she would get better, it would be a very prolonged recovery. She would get better, we would bring her home and there would always be more to do - some other complication that would add

something else. She pretty much tolerated -- I mean she did -- she really tried to do everything we asked her to do.

Kind of the thing that became another issue was she developed a pretty significant scoliosis that year to the point where she needed a brace and to -- for that to be even have a chance of being effective again they told us that there was no evidence to show that this would help in this case but it was the only thing they could offer. She will have to wear this really restricted brace for like 13 hours a day and she -- that was the one thing that she could not -- she couldn't tolerate that. We put it on her and she would just cry and then she would have -- we were having this feeding issue with the retching at that point so it's like we're putting pressure on her abdomen. And we were trying to feed her -- it was just -- I think that was kind of the point -- that was one of the low points. And one of the things I thought, well everything we are trying to do it's kind of contradicting each other. It can make these complications and what are we doing? That was one of most difficult things.

TITLE: A mom on the decision to put her daughter in hospice: we knew we could revoke it at any time and go back to the hospital. ... And then she said 'No Hospital.'

https://courageousparentsnetwork.org/videos/a-mom-on-the-decision-to-put-her-daughter-in-hospice-we-knew-we-could-revoke-it-at-any-time-and-go-back-to-the-hospital-and-then-she-said-no-hospital/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — shares the parents' journey from No Hospice to Hospice, from fear of Julianna dying at home to Julianna's articulate, spiritual insistence she stay at home. ... "We just felt like we had to honor that. We had the support of hospice; we knew we could call on them. We knew we could keep her comfortable and still there was that out if she changed her mind or if we changed our mind. That made it less scary knowing that we could make that decision."

Transcript:

Michelle: We did make the decision to put her into hospice but my intent was to -- the reason -- I was scared to death of her getting sick again and I did not -- the thought of being in hospice and dying at home was just -- I did not -- I didn't want any part of that because I thought it would be too scary, I wanted support, that kind of thing. So the only reason we agreed to go to hospice is because they told us we could revoke it at any time and that if she got sick again and we wanted to go back in hospital, we could do it. So that's why we went into hospice because there was that option.

So we went into hospice in like November, we'd had a really good winter. It was beautiful winter together and then like that, maybe the next February, she had a respiratory treatment that was uncomfortable and that had been the first time I had seen her suffer a little bit since all of those hospitalisations and it wasn't even anything -- I mean she had been through much worse but it really took me back to all that she had been through and how and it was really hard for me to see her suffer and be in pain. And that just made me rethink everything because I thought, "Oh my God, if we went back to the hospital and did the stuff that we did, again," I don't -- it just brought me back to that. I mean it had been a while so it was just -- I had to -- it just made me rethink things. So it made me rethink, is that what we really want to do? Do you want to go back to the hospital and all those treatments and that kind of thing?

And that night I was just -- we used to -- we would have to sit by her bedside until she fell asleep, which would take hours sometimes and so that was the time that was a very special time. Anyway that was -- it was my turn that night and so I just decided to ask her. I mean I don't even really know why. I decided to ask her but I just did and I asked her if she wanted to -- if we -- if she got sick again, would she want to go to the hospital or stay home?

Michelle: And she said very quickly, "No hospital." And I followed it up asking, do you -- well if you go to the hospital, it will give you a better chance of coming back home and spending more time with us. If you stay home that probably would mean you go to heaven by yourself and there will be separation from us. And again she said very quickly, "no hospital." And that really slowed me. I hadn't expected -- I don't know what I was expecting. I didn't really plan to ask her that but her answer came so quickly and so clear and with my follow-up questions I tried to make sure she understood it. She never wavered.

And that stunned me, and it led to more conversations with my family, with my husband, and so more conversations with her hospice nurse, asking what that would actually look like if she did get sick and she died at home.

And it made us realise that that I just felt like -- we just felt like we had to honour that. She had made it so clear. We had the support of hospice; we knew we could call on them. We knew we could keep her comfortable and still there was that out. We could, we could plan on keeping her home but we could still revoke it if she changed her mind or if we changed our mind, we could still -- we could change it. So I guess that made it less scary knowing that we could make that decision. We could have another plan but it could be amended again.

TITLE: A bedtime conversation: "Mom, tell me about the angels. Will they take me to heaven?"

https://courageousparentsnetwork.org/videos/a-bedtime-conversation-mom-tell-me-about-the-angels-will-they-take-me-to-heaven/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — reads a transcript of her conversation with Julianna in which Julianna asks questions about going to heaven. Exquisite, exceptional, courageous. A blessing. And Blyth reacts.

Transcript:

Michelle: This conversation she just -- it came out of the blue. It was her -- it was one of those nights when I was sitting by her bedside and Julianna said, "Mom, can you tell me about the Angels?"

"What about them?"

"Will the Angels take me to heaven?"

I don't know if I can do this without crying.

And I said. "Yes, I think so."

"Why does God send Angels?"

"I think he sends them so that we are not scared. Did you know that God loves you even more than dad and me? You know how he said that you will never be alone. God is the same way, you will not be alone and you will not be scared. You know this is true."

"Will you miss me?"

"Yes. I will miss you so much, I will be really sad but I will join you one day."

"Will I die in heaven?"

"No, we only die once, we get to live in heaven forever."

"Good I won't die in heaven. When you die, I will come and get you."

And I said, "I don't really know how it works Julianna but I think that you will be the first person I see when I get to heaven and I will be so happy."

And then she said "Do you want me to stand in front of the house and in front of all the people so you can see me first?"

"Yes. I'll be so happy to see you."

"Will you run to me?"

"Yes, and I think you will run to me, too."

And she said, "I'll run fast." And she shook her head back and forth because that is the only thing she could do to show me how fast she would run.

And I said "Yes, I think you will run so fast."

That's probably too emotional for this.

Interviewer: You know I cannot imagine how difficult it must have been to have that conversation with her and you know my daughter Cameron died at two and so it was -- so it caught me that we never -- we didn't even have conversations other than energy and the love conversations. And in some ways that made it easier because I didn't have to have the burden of hearing what she was afraid of or what she wanted and didn't want and because that was hard.

Michelle: Yeah.

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Interviewer: Also I'm jealous because you knew what she was thinking. And I'll never know what my little girl was thinking. And you know that she was thinking, your daughter Julianna was thinking peaceful, peaceful thoughts about Angels and seeing her mom again and running towards her and --

Michelle: It's actually a blessing, I mean it's a such a blessing to -- that we have this conversations and that she was able to share those and you know I think she thought about it a lot more than she let on like these -- these conversations would just always catch me off guard and it would always come at night kind of when I think when we are unguarded and I think maybe she would have talked about it more if she knew that it wouldn't upset me so much. But I feel they were hard conversations but I'm so grateful that we had them.

TITLE: Julianna's story goes viral ... and the impact of that.

https://courageousparentsnetwork.org/videos/juliannas-story-goes-viral-and-the-impact-of-that/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and

died at age 5 — explains how she began sharing the exceptional conversation she had with Julianna about her wishes and how the writing turned into a story on CNN ... which snowballed, and the range of feedback, judgement and comments she got, good and bad.

Transcript:

Michelle: The first heaven conversation just floored me, so I -- a few minutes after it happened, I just ran to my laptop and I wrote the whole thing down and then I just wanted to share it. I sent an email to my family and then I wanted to share more. I have no idea why. It just -- it was just -- I just thought it was so extraordinary and so I'd seen some stories that The Mighty -- from The Mighty, they were like on Yahoo News or something. And so kind of on a whim, I decided to just write up the conversation in one minute and then raise up the bit for publication and that was it. It was a little bit crazy.

And then about a month later, I got a call from Elizabeth Cohen from CNN and she is a health journalist and medical journalist and she had seen that story and she wanted to talk to me because she said that we are just starting to have the conversation about end-of-life care with adults but no one is really talking about it with kids and so that was very interesting, this piece, and that was her interest in our story. And so from there she came out to do a story on us which ended up getting a lot bigger than anyone had really expected and was a little crazy.

Interviewer: Can you explain why it got bigger and how?

Michelle: Well, it's like -- I know it went viral, that was bizarre or I mean -- from like within an hour of it I guess appearing on CNN, I was getting inquiries from media all over the country. They came to my work and our house and it was crazy.

And why did it go viral? I guess, I mean the headline was basically you know *heaven versus hospital* and it was the question that a four-year-old you know choosing. And so I guess that -- I don't know, I guess it's unusual.

And --

Interviewer: Well what's unusual probably, well first of all, the story in and of itself that they are even writing a story about this is unusual. So it's a good story. Secondly, it's well -- that a story like that I was told that I should say. It's also a rare that a four-year-old who --

Michelle: Shouldn't --

Interviewer: -- articulate about what it is she wants.

Michelle: Yeah.

Interviewer: And it's rare that her parents -- that the parents should be as mindful and supportive of their child's decision when that is -- well what it means is that the child is likely to not live as long. And so all of that I'm sure went into that.

Michelle: Yeah I think it's obviously the fact that we talked about it and it is those conversations. I mean I think that there are a lot of families who are going through what we did and a lot of them make that decision out of love and knowing that even if their child can't verbalize it, they know they are doing it for their child. They are making these really, really difficult decisions for their kid; but not everyone is going to have that kind of conversation to print and to remember and then not everyone is going to talk about that because it's extremely -- so it's like I mean you know it's a heartbreak; and to share it is really hard. And I think that sometimes people are afraid that there will be judgment and not to do that. People don't understand why they're making this kind of decision.

Interviewer: And you did get some judgments, didn't you?

Michelle: Yeah.

Interviewer: A, to live -- ta-ta-da -- little trolling people.

Michelle: Yeah. That was a shock too. When I first started sharing that on The Mighty I thought it was very naïve like I was -- I don't have -- like I wasn't even on Facebook. Like I don't even like -- I'm just not in that space so most of the commentary we got, I got after The Mighty was very supportive. But then there were a few -- there are a few comments saying like, "I can't believe that you'd let her, a 4-year old make that kind of decision. They are not -- they don't understand death." You know? I was asking leading questions, basically you know this I think one person even said, "This is just destiny." And again I was naïve but that totally shocked me because I guess in my mind, of course we've been living this. I knew what we've been through and how extraordinarily difficult it was to make these decisions and how we truly have her best interest at heart and I felt like -- I felt that she understood what she was saying and when she was talking about God's love. And she -- to me she gave -- she had insight. I think she knew what she was saying and so, there was no controversy in my family or with the medical team, like none.

And so it just took me aback that, "Wait, like they don't know." When I did -yeah, again I was naïve and if you are going to share your story publically, you're going to get that. So I guess I knew that that would be part of the CNN story too but it was -- it got -- it came, it was -- it got more exposure so then there was more.

Interviewer: And did you ever regret being so public, I mean did you ever regret letting CNN come to the story?

Michelle: A little bit. In the first few days when it went viral, that was really overwhelming because really we don't -- I mean journalists called my family like my mom, my sister and well it was crazy. And so it did feel overwhelming and I remember thinking that like when you share something -- when you share anything about yourself, you are sharing part of yourself, right? And so this is like a -- this is my daughter, and you know a secret story and so in a way I kind of felt like Julianna wasn't quite mine anymore like I had shared her. I mean I guess I wanted to share her but then now she wasn't all mine and it felt very strange. So I remember feeling overwhelmed and just wishing it would all go away.

But then like everything was the same. I mean she was still her, I was still taking care of her, we still had this and I was telling mom, she was still my daughter so everything was the same if I could just tune out what was going around and the things that were being said. There was still no controversy, no family in our -- within our medical team. And then I also thought, you know this stuff that people are saying like other families are going through this. Like I didn't know other families are going through this but I knew that it was happening and I knew there were other parents making these kind of decisions. And I mean it does need to be talked about because there should be no judgment, so, yeah.

Interviewer: Did you hear from some of these families?

Michelle: Yeah. Yeah and I still do. And which is incredibly gratifying and I've heard from them that they haven't been offered palliative medicine either. They don't know what it is, they see what their child is going through and their medical team just talks about more hospitalisations and more things that can be done and they have these questions and some have found our story that way, and just online and that's -- it has and it's changed the way the course of their child's care which is I mean, yeah, that is incredible to me.

Michelle: You know when you are going through this, you just want to talk to someone who has been through it. You want to know like, "can I really put my kid in hospice?" Like, "can I talk to someone else who has done this?" Like, "is this really okay?" And so I guess knowing that someone else has done it and the reasons why, it helps.

Interviewer: Has a parent actually written to you like, thank you. Has somebody said thank you for -- thank you for sharing, thank you for doing that and it's given?

Michelle: Yeah. Yeah, not just -- it's incredibly humbling. I got just that one like a few months ago and it's like you know she's gone about three years now, you know just, I'm very grateful that -- now I'm grateful we shared.

Interviewer: That was very brave. It was very, very brave. I remember when I first read the piece on CNN.com I admired you so much Michelle and both because of your -- and I was jealous, as I said because you had a daughter who could articulate what she wanted and well I -- my husband and I really felt we knew what she wanted, intuited. We couldn't KNOW KNOW KNOW

Michelle: Right.

Interviewer: Because she couldn't SAY SAY SAY

Michelle: Right.

Interviewer: And so I was jealous. I admired you and was sort of jealous in a healthy, happy way and then I admired you so much for being willing to go public with it and to share because I could -- I, because of the work that I was already doing with Courageous Parents Network, now I go, "This is going to help a lot of people." Yeah and obviously Elizabeth Cohen did a beautiful job of telling the story.

TITLE: "She was the closest I'll ever get to knowing what God is like on this earth because of the way she was."

https://courageousparentsnetwork.org/videos/she-was-the-closest-ill-everget-to-knowing-what-god-is-like-on-this-earth-because-of-the-way-she-was/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — talks about how her daughter deepened her faith.

Transcript:

Interviewer: So I want to go back to the role that your faith, your and Julianna's faith played you know for when you talk about heaven and God, was that because you had a practice in your home, in your life like a weekly practice or was that -- like how did that framework come into being in your family?

Michelle: Oh, good question. We grew up that way, so that's what we believe. And I -- when you have a sick child, you -- of course I don't think I've gone to

church in a long time, you can't. You know someone has to take care of her but that's definitely, it's our belief. And so I would say that having a child like Julianna, if I ever had doubts in heaven or doubts about a God like they were gone just because she -- there was just something so special about her and I know all children are special, yeah they are, but she was extraordinary. And I feel like in her, she was the closest I'll ever get to knowing what God is like on this earth because of the way she was. I mean she was just -- she was wise, she was so loving, she was joyful and yeah, she and her faith in heaven and because she really believed it too. I mean she -- part of -- some of these conversations, she was kind of comforting me which I hate to put that burden on a child but she -- but it was there.

TITLE: From a fear of a home death to feeling it was the right thing. And what to do with the room after?

https://courageousparentsnetwork.org/videos/from-a-fear-of-a-home-death-to-feeling-it-was-the-right-thing-and-what-to-do-with-the-room-after/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — talks about the evolution of her thinking about where it would be best for Julianna to die, and the critical role that hospice played. "Her room, her home was so important to her." "Now I can't imagine leaving our home." "Her room was like a character in her story."

Transcript:

Interviewer: You had been worried about home death, you thought definitely not at home?

Michelle: No.

Interviewer: There you were at home.

Michelle: Yeah.

Interviewer: Talk about that.

Michelle: Yeah, so I am thinking that if that just -- just this can't happen at home, it'll be way too traumatic. We'd immediately have to move because that was just, I mean I really that's what I was thinking and so I guess like after we had that conversation and we talked to our wonderful hospice nurse, you know I asked her specific questions about, "Okay, so what would this mean?" like, "Would you be able to come right away if we needed you?" "What would we do?" And we talked about medications, she talked about scenarios and she made me reasonably comfortable that we will be able to keep Juliana comfortable at home and we knew that she would -- someone would be there,

that kind of thing. And so when it happened, it went by -- it went really quickly. So she had another little aspiration event that again is unpredictable, and it did happen a couple of times, so even in hospice that we -- she'd have these things and she will be really sick for a couple of days, well we get her through it but it wasn't like that this time. So we did all of things we usually did and within 24 hours, we just, you know she was gone, and I don't think I knew -- I don't think I knew it was going that way till maybe, I don't know, six hours before she actually died. But she was comfortable. She was in her room which was so important to her and her family was there. And I feel very grateful that it happened that way and I think that her room and her home was so important to her, I can't imagine taking her to a hospital for that and I know that for some families that's the right place to be and they need that support, and it's just different for everyone but for us, it was absolutely -- it had to happen, it was the way I think she wanted to. It was actually really peaceful and I am very, very grateful for that. And it's funny now, now I can't even imagine leaving our home, like if we have to move one day, I don't know how we'd do that.

Michelle: Yeah, so her room is very special. So her room is the princess room that was for Make-A-Wish. So they -- most people go on a trip but we -- she -- we can go anywhere, but she wanted a room. So her room it's like pink sparkling walls, it's like really, it's like beautiful furniture and so it was -- her room is like I remember like it's a character in our story almost. She just loved it and I mean it was part of the magic of that year when we were in hospice and you know it was just a big deal. A few days after Julianna died, Alex just moved in there. Like he on his own, we didn't say anything, he just decided he wanted to be in there. Part of it may be just because it's close to our bedroom, I don't know but I do think that he feels some comfort being in there. And he is a boy, he is like 10 now and it's still a pink room and I think that, I don't know, I think that you know we've asked him like does that bother him a little bit and I think that he -- maybe a little bit but I asked him if he wants to change it, he said no. I mean he seems like -- I think, we are not ready. I don't know when that day will be but yeah it doesn't bother him I guess.

Interviewer: That just makes a lot of sense to me.

Michelle: Yeah, I think we all feel comfort just being in that room.

Interviewer: Yeah.

Michelle: And I think she would really like that it's still being used.

Interviewer: Yeah.

Michelle: Yeah.

Interviewer: It was quite a few years, it was a few years -- it was a few years after Cameron died that we changed the bed, so it was no longer the bed she had been in. We had two new beds. We had -- we inherited these other nicer twins. They are like, oh, so we put them in there and that was kind of a big deal to lose her bed which was not some great bed, it just had been her bed.

Michelle: Right.

Interviewer: That was a deal. And then you know for us it's been 18 years and it's still her room which is not a guest room, and there is all the art that was on the wall during her life, is still on the wall. We've changed everything that's on the floor but the stuff that's on the wall, that I remember looking at when she was -- when I would spent all of the hours in her room and I felt like maybe she knew what's on the wall in her room, still on the wall in her room. These are the things.

Michelle: I think some things just feel right, and I don't know.

12 TITLE: Bereavement: What to do with my daughter's STUFF - toys, clothes

https://courageousparentsnetwork.org/videos/bereavement-what-to-do-with-my-daughters-stuff-toys-clothes/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — talks about the thoughtful way the family gave away her beloved toys at her service. The clothes are hard, especially the princess dresses.

Transcript:

Interviewer: Are there things of Julianna's? What have you saved of her stuff and where is that stuff?

Michelle: She had a lot of stuff. So many of her toys we actually gave away at her tea party, so there are a lot of children who went to her tea party and so we had a big table that we had and a square box and so we had a lot of her toys and we asked each child to take one and there were very specific rules about what to do with these toys because she -- toys are not just toys to her, she really, even though she had a ton of them she treasured them, she knew where everything was, that kind of thing. And so some of her rules were like, they'd have to have a name. If you are watching TV, they have to watch TV with you, you have to welcome them and so she would do that for toys. So we wrote out kind of a list of rules and take a toy but these are the rules and so we moved on a lot of her toys that way and I trust that they've gone into good

homes. We still have a lot of her stuff. Her clothes were hard, I think that's just something well recently I tackled a little bit, especially difficult are her princess dresses because she had these special dresses that were kind of fancy and I can't just give those to goodwill. So --

Interviewer: You'll never give them away, you may hold onto those dresses forever and ever.

Michelle: Maybe, at least some of them. Yeah.

Interviewer: I have two dresses of Cameron that will never go away. They will just -- and they are in a closet and I find them -- it's very comforting.

TITLE: Bereavement: how is the rest of the family doing – son, husband? Talking about it!

https://courageousparentsnetwork.org/videos/bereavement-how-is-the-res t-of-the-family-doing-son-husband-talking-about-it/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — talks about how her son and husband are doing, and how hospice has helped with grieving. You can't think about, "how am I going to get my other child through this?" it seems impossible -- that's what grief counselors can help with because it needs to be talked about with your child, and you need that outlet too."

Transcript:

13

Interviewer: How is Alex doing?

Michelle: You know I think one of the really huge benefits of hospice is that he was in grief counseling for a year before she died. And without that I don't know how he'd be doing. He is doing -- I think he is doing remarkably well, but we were talking about it. He was there when she died and he wanted to be there. And we talk about her all the time and so I think he is doing -- I think he is doing as well as he could -- can be.

Interviewer: So you had asked him, well firstly I'm glad to hear that, but you had asked him, "Do you want to be there when Julianna dies -- when your sister dies?" You'd actually asked that question?

Michelle: I think we talked about it and then when we knew that night, we told him and we asked, you know we asked, if you want to be there and he wanted to be there for part of it. So, yeah.

Interviewer: And obviously, I mean as evidenced by his desire to sleep in her bedroom, that it was not traumatic -- it was not traumatic for him?

Michelle: It's -- yeah that's the amazing thing. I think that you think about -- you can't even think about the stuff, right? It is too hard.

Interviewer: Impossible to imagine.

Michelle: Oh, it is.

Interviewer: You can't -- you can't simply imagine.

Michelle: You can't think about it for yourself and then you can't think about, "how am I going to get my other child through this?" It just seems, you're right, it seems impossible and I think that's -- that's where things like hospice are for -- for that's what grief counselors can help with because it needs to be talked about. I mean I know that he was thinking about it. I mean he is an intelligent child, we were in the hospital all the time. Of course he was thinking about it, of course it was scary. I think the worst is when you're thinking about it and you can't talk about it. But to be able to talk about it, with your child, you have to be able to talk about it and you need that outlet too. So I think that's one of the essential things that hospice gave us.

Interviewer: And now switching to looking -- well, no, pause, how are you and your husband doing?

Michelle: We're doing -- we are doing okay. I think that we've had our different paths for grieving. I think that's -- I mean that's normal. I think that again because as a family, we were -- we had palliative medicine and then we had the benefit of hospice. This is never easy and you know it's -- even though you prepare for it, you can't really be prepared and grief -- a loss like that taking all the different kinds of directions. I think we're okay, we're stronger as a family together for having gone through this.

Interviewer: I am very glad to hear that.

Michelle: Yeah.

Interviewer: And I do -- your case just sort of reinforces my conviction that the better the before the better the after and you got all the ingredients possible for a good before and here you are doing as probably as okay as people can be after such an extraordinary loss.

TITLE: A Mom/MD reflects on how her daughter's journey has impacted her own practice of medicine.

https://courageousparentsnetwork.org/videos/a-mom-md-reflects-on-how-her-daughters-journey-has-impacted-her-own-practice-of-medicine/

Description: In this Zoom interview with CPN, Michelle — a neurologist herself, and mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — reflects on how her daughter's journey has impacted her own practice of medicine.

Transcript:

Michelle: They -- I have always been kind of drawn to that part of medicine. I mean being neurology, there are a lot of things that aren't going to get better. Many neurological conditions are devastating and so that had always been something I -- not that I enjoy in my practice, but I thought like that was something, that's part of my job as a neurologist like helping patients through this kind of thing. And so having gone through what we did, very ironically a neurodegenerative condition, and it being fatal, I empathize even more with my patients. I know a lot more about what it's like to be a caregiver and that's something that we are all exposed to in medicine but until you've done it, you have no idea what it is like to be a caregiver and for someone who is totally dependent on you, and the strain, physically, emotionally, financially, everything. And I know that my -- when you can't -- it just can't be one person doing it and there are people out there that are doing it like that. So I'm a lot more sensitive and tuned for that. And so I think, I ask maybe some different kinds of questions than I did before.

And I try to -- try to find more resources, there is not enough. But yeah, I know a lot more what people are going through and how trying, if you're a caregiver. That's probably the biggest difference. I've never been afraid to have the conversations that you know as a neurologist you have -- but I'm even less afraid of it now because it's even harder when it's a child.

15 TITLE: *One day you are going to be that person for someone else.*

https://courageousparentsnetwork.org/videos/one-day-you-are-going-to-be-that-person-for-someone-else/

Description: In this Zoom interview with CPN, Michelle — mother of Alex (age 7) and Julianna, who had a severe form of Charcot-Marie-Tooth disease and died at age 5 — talks about what a difference fellow parents and providers have made. "I guess I'd rather not know you but it's really amazing, the people you meet and how they can help you; and then one day you are going to be that person for someone else, right?

Transcript:

Michelle: It's so hard but there are other people who've been through this and this community that no one wants to be a part of is an extraordinary community. And there is help even though it seems impossible. And I think going through something like this, I feel like in our case and I think in many people I talked to it just exposes you to some people who are truly I think angels on earth in the hospital, caregivers, other parents and I wish we didn't have to go through this. I'd rather, I guess not know you because I didn't have to go through this but it's really, it's amazing the people you meet and how they can help you and then one day you are going to be that person for someone else, right?