Sandy Clancy

Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of 5.

1	Title: From diagnosis to death: "It was 8 months of an incredible psychological terrain."
	Youtube Link: <u>https://youtu.be/8CEZ_MaXRIM</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic.
	Transcript: Sandy: My name is Sandy. My son Jack passed away fifteen years ago now, it's been a very long time although it feels like yesterday. So, he was a normally developing 5 year old, he had hit all his milestones, no major health problems. And just around his 5th birthday, he began to have very bad headaches and very bad stomach aches, and we took him to the pediatrician many times and nothing seemed out of the ordinary until probably the 6th visit to the pediatrician where he noticed some changes in the pressure in his eyeballs. So, we then started this odyssey, and to keep a very complicated story rather succinct, he was eventually after 8 months, diagnosed with a rare and always fatal blood disease called Kohlmeier-Degos disease. He died at the 9-month mark. So it was 8 months of going to the emergency department, inpatient stays, PICU stays, time at home, and then finally two months in the PICU at the end. So it was just a complete and utter whirlwind, and one physician that we got to know quite well, said, "at the beginning of this when I first met Jack, if you had told me that in 8 and 1/2 months he would be dead, I would not have believed it." So that was just an incredible sort of psychological terrain.
2	Title: I convinced myself my job was to be competent. I was 'at the table' and it was a lot of pressure.
	Youtube Link: <u>https://youtu.be/TkVMhHgj6RU</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy talks about her feeling pressure to be knowledgeable and forever present – which took a serious toll.
	Transcript: Being in the hospital is like no other experience, and it's really multidimensional. So, this is what I would say; throughout his illness I convinced myself that my job was to be competent. My job was to do all of the complex

	discussions about medical procedures and that I did not have a problem. There was nothing that was going to personally about me get in the way of that. So if I had a headache, if I had a stomach ache, all of that just didn't matter, right ok. And very interestingly I thought about this a lot, we were lucky enough to have the leader of the team, the leader of the medical team, very graciously say to me, "we regard you as a member of this team. So we have a neurologist, we have a rheumatologist, we have a gastroenterologist, we have 15 different subspecialist, if you conceive of them at the table, you're at the table too, and we need you and the expertise that you have is that you know your son really really well." And that was a beautiful thing and I'm glad that that happened, but at the same time it was pressure. And so I do recall, you know, him making rounds this doctor he would come in at 10 a.m., you just never knew, and if there weren't a resident around that you could ask a question to, he would come to me and say, "hey, what's going on today?" and I always felt that I wanted to know the answer, right. I do remember feeling I am exhausted and I really need to sleep, but I can't do that right now. I again, you know, I remember one PICU attending saying, "you should really get some sleep" and being irate that he had suggested that. And I couldn't even tell you why I was irate Well I think I thought, my kid is dying and you're telling me to go get some sleep, I find that trite at the moment. And so, I think the toll of that was that I didn't really pay attention to what was going on with me, what my experience was like. So being in the hospital is just you know, you're sleep deprived, you eat awful food, you are hyper-vigilant, especially in a Pediatric Intensive Care Unit. This was an issue for me they were all shared bathrooms which just is important to me, you know, that was sort of a thing. So the experience was, and then of course, you know, Jack died, so I just feel at the end of it I
	nine month journey, so just trying to adjust to his death in the context of what I
	would say was trauma, was really really difficult.
3	Title: "I internalized that to be competent meant not to cry"
	Youtube Link: <u>https://youtu.be/5K2MQcrapWY</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of 5 – only 9 months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy shares that not letting herself cry may ultimately not have been helpful for her. "These are imponderables."
	Transcript: During one of the admissions when I think we had had an outpatient visit and it was turning into an inpatient visit, meaning that the doctor who is taking care of him said this boy needs to be admitted, and so in the course of sort-of the paperwork to get all that arranged, I started to cry and the doctor said,

	"don't cry, don't cry. This is going to be fine, but don't cry." And that message to me was pretty loud and clear, which again, was this message of this is the subject, you know, your child is a subject of the care here so you just hold it together. And I actually, there was another instance as well where I think a surgeon or a neurosurgeon was explaining the changes that were taking place in his brain, and it was just terrifying, and again I started to cry and he very gently said, "don't cry, don't cry." And I think in retrospect it's really complicated why people say that. I think it's partly they're trying to maintain their professional demeanor, and all power to them for that. I think maybe it's like, I have one issue here, I don't want to have two. Or maybe they were trying to console me and say, actually there's no need for that level of fear or that level of sadness because this is going to be okay. I really don't know, but again, the message was, just be competent, just be okay. yeah, I imagine what would it have been like if I had said, you know, "I'm going to excuse myself" or "this is what I'm going to do" or "this is hard for me" as opposed to just taking the message, you know just taking the message. And I do think these are imponderables, I really do, because I think you do what is needed at the time to get care, really good care, for your child.
4	 Title: My grief was exacerbated by the trauma of being in the hospital in a really intense setting. Youtube Link: https://youtu.be/8_3ASzlJiQ4 Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of 5 – only 9 months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Transcript: So we had a really interesting circumstance that we were at one of the major academic medical centers in the country and the consensus, of most of the medical team, was that they could figure out what was going on and find a cure. And I had my doubts about that, but certainly went along with that because how could a mother not go along with that. So I would say we went with that theory until probably about four days before he died, and then it was pretty clear that he was going to die. So that is not a lot of time.
5	My grief was exacerbated or complicated I think, by the trauma of being in the hospital in a really intense setting and then I would also say with anxiety from that experience and also just from a child dying, and I think, you know, when you're in the hospital in the PICU setting I mean you know, Jack had some procedures that were that, put it this way, we wouldn't have agreed to it if we thought he was going to die, you know. You put your child through things that you otherwise absolutely wouldn't and they're hard to watch. And then of course you have those lingering doubts and you have guilt about that. Title: Getting out and walking was a saving grace.

	YouTube Link: <u>https://youtu.be/UDGS6MN85mE</u> Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare
	blood disease Kohlmeier-Degos and died 15 years ago at the age of 5 – only 9 months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy talks about how helpful she found it to get outside and walk and reflect.
	Transcript: I have always been a walker. I mean I think walking, that was the one thing that I did throughout. I would make sure that somebody was with Jack, my husband, or a friend, or sometimes a volunteer, and I would walk and that really allowed me to sort-of rest my brain. I have recollections of walking around Beacon Hill and just really not being able to see because I was crying so hard, but that is a memory that I think was That was an activity that really really helped. It sort-of allowed me some kind of catharsis to just get away, get out in the sun, walk by the river and sort-of see the water, and then just kind-of reflect on what was going on rather than being in the middle of it. So I absolutely think of that time as a saving Grace, of getting out as a saving Grace. And that wasn't even
	something that I thought about. It's really just kind of It was just kind of intuitive for me. It was something that I just felt like I had to do.
6	Title: I think worrying about past decisions, the past, does have an effect on your body. Yoga felt good.
	Youtube Link: <u>https://youtu.be/U9TkWlP6ziE</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy talks about how feelings of regret showed up in her body and how yoga has helped.
	Transcript: I remember going to yoga often and I sometimes would go early in the mornings before the sun came up, and I got to know one particular teacher and she said one morning, after I think she felt that she could and maybe after she knew my story, she said, "you know, you are carrying this, and your shoulders are sort-of slumped, you're sort-of caved in like a C" and she said, "that is your grief and your pain." And I so appreciated her pointing that out and I think that was really key to me then beginning to understand how we hold all this stuff. We absolutely hold all this stuff in our bodies. I have always been athletic I would say, but never had really thought about emotions in the body, but yoga, and especially the really physical kind of yoga, just felt good to me. It just felt good.
	One particular morning it's so funny how you remember these things even fifteen years later one morning you know, this particular teacher you know, she just said some words at the beginning before you start practice and she said, you

	know, "this present moment is the only one that exists. The past really doesn't exist anymore and the future doesn't exist. This is the only moment." And that was just like a boom for me because I had been going over in my head, did we do the right things? Should we have made different decisions? All of that sort of stuff And then, you know, what's going to happen in the future and who the heck knows what is going to happen in the future. But just in that moment I had this image of, I have a kind of choice today, like I have a choice now when I go home and I make breakfast for my three-year-old, you know, I have a choice about if I'm really here, am I present right here with him, and what do I want his breakfast today to be like? And I didn't want his breakfast to be me zoned out, you know, walking around my kitchen not being able to focus and you know, my husband doing the same, you know.
	So that was just really profound. And I mean, I am by no means an expert in the mind-body, I really am not, but I try to do as much reading as I can, and I do think those pers what's the word I'm looking for I want to say perseverative thoughts that go over and over like, did we do the right decision? You know, Do I feel guilty? I'm not sure if I feel guilty All of that I do think that takes a toll on your body so if you can kind of free yourself up from that worry about the past and the worry I think it does have an effect on your body.
	The yoga, I'm telling you, the yoga in terms of my systems, everything felt better. I was able to sleep at night which was key, I was able to because I feel like when we were in the hospital I just got kind-of deconditioned. I just felt the food that I had eaten was so bad my posture improved, like you know you stand up a little bit better, and then of course when you stand up better you feel better, that whole thing. You just start feeling more yourself. I actually ended up doing a yoga training and there is just a lot of discussion about your emotions and things that get stuck, and not allowing things to get stuck, whether they be feelings in your body or emotions that you have, sort-of just letting things flow through, letting life flow through, not controlling so much. Again, easier said than done, but nevertheless it injected a kind-of goal or an aspiration someplace maybe to get to.
7	Title: My present self message to my past self: "You are doing a good job. You can take a rest."
	Youtube Link: <u>https://youtu.be/9Qg9GlgfG5U</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic.
	Transcript: If I could send a message to myself, way back when I was going through all of that, this is what I would say

	"what you are doing is extraordinary. The fact that you are upright and breathing right now in the midst of what is going on is extraordinary, and there is not one single thing that you could do more for your child, you've just done it all. And I wish and hope that you would take a moment to care for for yourself" and I don't even really like these words as I'm speaking them, it's an approximation, because I don't know how I would react but yeah, "it's okay, it's okay to go take a shower, to go for a walk" and I think that parents would need assurance that they will be updated about anything that's happening. But I think it would mostly be that you are doing a good job, you really are. So you can take a rest, you really can take a rest.
8	Title: I think any kind of physical movement is imperative.
	Youtube Link: <u>https://youtu.be/RQPxpPKSW_A</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy shares all that she has learned about how physical movement and breath can help a person process their grief.
	Transcript: I think that any kind of movement is imperative, I just do. Whatever it is, if it's walking, running, dancing, whatever sports that you like, swimming, right. I saw this I'm just going to talk, I'm just talking so this amazing interview between Brene Brown and sisters, so two young women, and they wrote a book called <i>Burn Out</i> and they talk about how we have a stressor, okay there's a stressor, and then your body has a stress response, and what you think is that when the stressor goes away, the stress response goes away, but it doesn't. It has a natural flow and you have to kind-of consciously workout the emotion somehow, and so you think I finished that big paper now I'm good, but your body doesn't know that that thing is over, so you're still revved up about it, and so the best way to complete the cycle is to move your body. And again, it's like running, dancing, just whatever it is.
	And the other thing that I learned at a workshop that I went to is that all over the world, and this is a very ancient technique, is that after something intense happens people in a community, or in a group, shake have you heard about this this shaking, you just shake your whole body like with your feet hip-width apart, for like 2 minutes and apparently it's a way to get through the emotion and get through trauma, it releases Trauma from your body. Breath So it's, move your body, shake, and breathwork that will complete the cycle. Getting a hug from somebody completes the cycle. Being with somebody who you really love and really like, basically those activities tell your nervous system that you're safe, right, that it's safe, you're good. You're good now, the threat has passed, and that to me has really helped. I've only done it for like two months or so, but it's allowed me to gain awareness. So, let's say something stressful happens and then I say to myself okay, it's over, but I still have to work that through my body, and I

	do go for a brisk walk or something. And the combination of knowing in your mind and having it go through your body seems to work for me.
9	Title: Meditation has been important for me.
	Youtube Link: <u>https://youtu.be/oBHocUbr_ZA</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy shares how deep breathing and meditation helps her quiet her mind and anxieties during bereavement.
	Transcript: Meditation has been really important for me. Not that I'm a great meditator, but I think the ability to quiet the mind has been very beneficial to me, and also I think it helps with your body. And especially at night, if I have trouble falling asleep, I can do just a simple five counts in and then five counts out, and five counts in and five counts out, and if you focus on those numbers I tend to focus on one, two, three, four, five, going up and then five, four, three, two, one coming down, or something like that if you focus on those, then you don't think about whatever is going through your head about your meeting the next day, and before you know it your mind can settle, your body settles, and then you can fall asleep. And similarly there are the progressive relaxations. So you start at the tip of your head and then you go down to the tip of your toes and you relax each part of your body, I think those have helped me to.
10	Title: Hard terrain for anyone being to navigate: What am I in control of? What is the universe in control of?
	Youtube Link: <u>https://youtu.be/0mx-eR0LnCg</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy shares that she thought she could control the outcome for her son, which took a toll on her well-being. "There's just no way to know."
	I thought when Jack was sick that every single move I made, every single decision I made, was life or death and that if I made the wrong decision, that he would be worse or he or he would die, and then if I made the right decision there was a chance that he could survive and maybe even thrive. And so every I had a sense of control which was misplaced in the sense that we do have control over taking care of our children in the sense of comforting them, you know, making sure they're comfortable, we do, but in the big scheme of the universe we really have no control. I did not have an awareness of that and I think that that would have eased my burden. In fact, I remember it was probably like two days before Jack died, a lovely older physician took my hands and he did say, "it's all in God's

	hands now. It's just in God's hands." But the point is it had been in somebody else's hands from the very beginning. And that is a hard terrain for any human being to navigate. This, you know, what am I in control of, what is the universe in control of? But that is a piece of advice that I would impart to myself way back 15 years ago. And I think it would have allowed me to take a deep breath and been like, you know what, at the end of the day, I did the best that I could today to take care of my son. But in the big scheme of things, we just don't know, there's no way for us to know. So, that is something that I would say.
11	Title: Rituals and anniversaries – How we remember Jack.
	Youtube Link: <u>https://youtu.be/dIsBFgt0Q-Y</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Here Sandy shares how her family celebrates his birthday and anniversary of his death – balloons, beach, beef.
	Transcript: Yes, so for a few years after Jack died we had people out to our yard and we released balloons and that was really appropriate for his little friends who wanted I don't know if they wanted, but certainly leave their parents wanted a way to mark the day and it was great. And then a friend of mine said could you please not release balloons because it's not so great for the environment, but at any rate So, what we've taken to doing on the day that Jack died is to go to the beach, like the three of us we go to the beach and that is super comforting because it's a place that we all like, and he really liked the beach too. On jack's Birthday, we always have beef stew because he loved beef stew is his favorite meal, and we have whoopie pies because that was his thing, like the two were his thing, and then we say a few words, we each say a few words about him and those are the rituals.
12	Title: Bereavement Grief! A big empty hole.
	Youtube Link: <u>https://youtu.be/m9eQPsxdxeM</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of 5 – only 9 months after his diagnosis, most of which was spent in the ICU. The experience was traumatic. Sandy describes her grief during the first few years after Jack's death.
	Transcript: I just remember grief being, I don't know if you had these experiences of just going to the grocery store, getting back in the car and just falling apart. You just fell apart and then it's just this big empty hole and you can't even see the next step, which is just to drive home, you can't even see that or even conceive of how you could do that, or why you would even do that. Like it's just, it's just

	overwhelming in total. Right, so it's sort of like you're driving in a rainstorm I guess, and you can't see. And now, I don't think I'm at the I don't know, I'm not at the end of the journey yet. It's still a journey, right.
13	Title: I needed a narrative: it was helpful to go through the medical records and make sense of it
	Youtube Link: <u>https://youtu.be/kUamPTlmrRg</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic.
	Transcript: what was helpful in my grief process, was to write down everything that had happened and I actually ordered the medical records, and I saw all the medical records, and I placed them in order and I put notes next to them, and I think the reason I didn't even know why I was doing this and I think the reason was to make some just plain old sense out of what had happened because it had been so surreal, and otherworldly, and confusing that I just needed a narrative. So I think making some coherent sense out of what just happened is very helpful in the grief process too.
14	Title: A bereaved mom: 'It was important to me to stay in contact with some of Jack's providers.'
	Youtube Link: <u>https://youtu.be/aFKVb9sQObc</u>
	Description: Sandy, mother of Jack and Ben. Jack was diagnosed with the rare blood disease Kohlmeier-Degos and died 15 years ago at the age of $5 - \text{only } 9$ months after his diagnosis, most of which was spent in the ICU. The experience was traumatic and Sandy shares that staying in touch with those who knew her son and her in the hospital helped her with her isolation after his death.
	Transcript: it was important to me to stay in contact with some of the providers who had taken care of Jack. And again, we were in the hospital for that two solid months and I would say the Residents, you know they rotated in, and you know because my husband and I were there pretty much all the time, well one of us was there all the time, you know you'd be there late at night and you would talk to the resident and you would then find out that that person's father had died when she was 14, and while the discussion wasn't about the comparability, if that's the word, of the losses, there did develop a shared sense of the loss. It's sort-of or, a better example would be maybe they were an intern, and they hadn't experienced the death of a child yet, right and so there was in no way a sense that I was taking care of them, but just talking to to them, you know and sharing humanity and going through an experience together. So at any rate, afterwards just connecting you know keeping in touch with them like maybe going for a walk or just

exchanging an email, or exchanging a card, I found that very very helpful because I felt a lot after Jack died that the world as we have set it up isn't so comfortable with the death of a child.
I mean, I would bring my younger son back to preschool and there were certainly a lot of people who expressed their condolences, but then there were some people who I knew, knew, and didn't say anything, and I get that because they felt uncomfortable, but you feel alone. You feel alone like I am the only person that this happened to when you kind-of intellectually know that that's not true. And so feeling like you went through it with people, and people who were in the room, you know, they were right there with you, is very very comforting.