

## Kim's Words - Celebration of Life

First, I would like to say how proud Matt and I are of our three sons. It's a proud mamma moment. And next, I would like to tell you that the outpouring of support -- the depth and the breadth of the support -- is beautiful, and it helps so much. I would say it's indescribable, but actually, Ben's best friend, Michael, actually described it for me. There are orange ribbons everywhere in Sequoyah Hills and on Kingston Pike, and I can't tell you how much the orange ribbons right at the crash site have helped me get past that every day. So when Michael wondered why Jodie, his mom and my dear friend, was putting a ribbon on the mailbox (Michael happens to also have autism.), she told him about Ben. Well, it's for Ben, his best friend. Then they got in the car and they were going around the neighborhood and Michael described it perfectly because he said, "There's Ben. [pointing each time] There's Ben. There's Ben again." And that's how I feel -- that Ben is everywhere. And long after those orange ribbons come down, every time I see orange, I will see Ben. And in this town, that's about every second. As I said to Matt when we moved to Knoxville. "Honey, it appears I've got a light load, a dark load, and an orange load for laundry." And it has been that way ever since.

And I would like to thank Dr. Brunell - David Brunell. He was actually *my* teacher first. We moved here, and I was 38, and I said, "When I turn 40, I'm going to get back into my piano." And so he was my teacher. I don't read music very well. I should, but I had the Ben Ears and he was patient with me. And the arc of the pieces in today's program are important because the Brahms is, I think, my favorite piano piece in the world. I have not mastered it yet, but I will. And I love it so much. And every time David would have a recital, I'd say, "Hey, you're going to play that Brahms at the end, right?" It's so beautiful. Then the Grieg that he played for the reflection, he taught to both Ben and me. And by the way, after I obviously took lessons, I realized what a gifted teacher he was, and I signed all the boys up. So Ben, Miles, and Coleman have all been taught by Dr. Brunell. And um, Matt, you got next? Are you gonna...? So I played the Grieg. And, you know, at first Ben couldn't handle even five minutes of really a lesson. But we kept working and kept working. And wouldn't you know, he ended up playing the same song that's really at my level. And he played for his professional gigs. He's played that Grieg many times. So we share that piece. And the last piece you're going to hear at the end of the ceremony is the Tennessee Waltz, and he learned that much to the absolute joy and delight of the residents in the assisted living centers: Windsor Ridge, Echo Ridge, Trinity Hills, and others.

David represents the beautiful portal of music and music teachers. And it is very comforting to have known that probably the last person Ben had a conversation with was David. I feel he [Ben] had a portal to Heaven - not to go in there, but to watch. Because he would narrate conversations between Matt's mom and Freddie Mercury. And it was absolutely for certain what they were talking about, as they walked, Basie and Ellington, our dogs. So he had that portal with music, as Miles talked about. And there are so many teachers - he had three cello teachers, string bass teacher, drum teacher, and wonderful music teachers in Richmond, Virginia, and obviously in Knox County Schools.

So if you're looking at your program, you're wondering what Circles Around the Son is. It's actually the song I wrote for Ben. And he was one of the first people to hear it two years ago after it was recorded by my a cappella singing group (but while I was in the eighties) - so the current a cappella group recorded it. In 2021, they weren't able to rehearse or perform [due to Covid], so when Coleman tore his pec and they let me into the Duke bubble, I met outside with Out of the Blue and said, "Hey, I've got a project maybe that you all could do." And I arranged it - the song - for a cappella, and they recorded it and I played it for Ben so many times, because when it got to the mixing stage, the production, the wonderful friend - another David, in Chapel Hill - would send me the versions. And so as we were going back and forth to Duke Swim meets usually over the mountains, we'd be - I'd be listening to hear how I wanted it edited. And we talked about, I said, Ben, this is the song I wrote for you. And he liked it. And it was debuted just in an Out of the Blue reunion in 2022. Only very few people, some of whom are here, have heard it. So it's - it's actually Circles Around the Son S-O-N. And you'll see in the video because you're going to listen to it and watch it. Mhm. Yes, you are! You're my captive audience.

It's called my Floortime Song for Ben, and I'm going to give you a little bit of background that I gave Ben. I said, Ben, when you were diagnosed with autism at age two and-a-half, like any parent with a child with a disability discovered at any age and stage, it's a - it's a call to action. You have to do something. And with autism, you know, he was showing signs of not participating. He stopped using words as language. He could label them - he could spell them, spell them backwards - But he lost that ability with language, and we had to get it back. And so my wonderful cousin, Alan Shapiro, who worked with a lot of students with special needs, *showed us* Floortime. And in essence, it's playful obstruction. And we were in Newton, Massachusetts, and he - Ben had just been diagnosed, we were sort of reeling - and he played with a ball. Ben wanted a ball, and he kind of wouldn't let Ben pass him. And Ben was frustrated at first, you know, Hey, who's this dude? I want to do this. And he playfully obstructed. And after about a minute, Ben started smirking. And he got a sparkle in his eye, and he looked at Alan, and I was sold. So I read the whole book called *The Child with Special Needs* by Dr. Greenspan. And Ben lined up cars everywhere. Our house looked like a museum of lined up cars that you would discover under the bed, on the windowsills, everywhere. This was what he did to go sort of within himself. And we used that to go into his world, playfully obstruct, so we sort of encouraged what they call "circles of communication." And it worked. It's scary to go into a child's world when that's the scariest thing -- you're trying to get them out. This approach became our philosophy for all our kids, and I'd like to think everybody we know. We will meet you in your world, connect with you, and we will dance around and find common ground and have circles of communication.

There's also what's called - and you'll hear this in the lyrics, which is why I'm [telling you this], and I explained this to Ben - a ladder. A social emotional ladder. That if you've got a kid like Ben who is removed, they might not get the typical social emotional levels, and you have to get that back. So this was a - it was scary because we wanted to pull him into our world, and we did it this way. And that is what -- I made up this melody when he was two and-a-half to remind myself: We will make circles around the son. We will make circles and circles and circles around the son. And everything we did was about this approach.

So big reveal, Knox County, for those of you who know me... Most people in my past life know me as a musician. Not so much in Knox County. They know me for other reasons. But the reason they do - and they know the boys for music. We have some of the best- I got the Star Chamber music teachers for all the boys, but not me. I put that to the side because this was so important. So my big reveal is that Floortime was the reason I fought so hard just for Ben's basic rights. Because what I saw was that in school, he could have circles of communication all day long while learning the general curriculum. And I *had* to have that happen, because we needed him to have the most positive outcomes. And it just so happened that his educational rights matched *right up* with Floortime through his IEP. Accommodations: utilize interests, utilize musical and rhythmic strategies... It's individualized, and I knew it would work, and it *did*.

So. This is a little vulnerable for me. You're going to hear the song, and you're going to see a lot of pictures and videos. Remember, I finished this -- It took me 20 years to write this song, and I'd forget about it sometimes. And it came and it came... And I'll tell you, when I did finish it was the night he stayed by himself in his apartment as part of the UT FUTURE program. Matt and I went to a Lady Vols big event in the convention center, and it was his first night staying alone. And you'll even see pictures of that because we're a little bit dressed up. And he was going to stay by himself before his roommate moved in right behind Sunspot. In those condos. And we were scared. We cried in the parking lot. What are we doing? Isn't he about eight years old developmentally? But we took that leap of faith. We gave him his dignity of risk. And the next morning, I came over and he was okay. And that's when the rest of the song came flooding. If you saw me on Cherokee Boulevard jogging with tears streaming down my face, that was that era, because it just happened. And that's when I finished the song. And lastly, before you hear it (big buildup), when I arranged it for a cappella. I didn't intend -- I'm a vessel of music. I don't - I don't think about it, it just happens, which is wonderful. Um, the piece that I arranged for our wedding in Duke Chapel almost exactly 31 years ago was Corinthians 1:13. Love is patient and kind. And that just worked.

And I'd like to give you a little Floor time thought: When we think of raising kids with disabilities, it's usually about us. Our patience, our kindness. What we're enduring, what we're hoping. Well, flip it around. Go into their world. What about a person who can't communicate? Who's patient enough to wait for us to figure out how that person can communicate? Who's patient and kind? Who is not insisting on his own way or her own way? Who bears all things, believes all things, hopes all things, and endures all things?

All right, Y'all. Ben liked this, and I hope you do, too.