

Raising a Family When One Child Is Living With a Rare Disease

Avram & Monica, caregivers • 13 minute read



Keep in mind that Hunter syndrome affects everyone differently. These stories do not reflect all the possible experiences that someone may have with this condition. Also remember that your healthcare team will always be your best source of information.

Monica and Avram are parents to 3 wonderful children. Because their oldest son, Kalel, is living with Hunter syndrome, they've never thought of themselves as a "typical" family. But it's this difference that has brought them closer together. In this interview, Avram and Monica talk about the impact the disease has had on the family, and about the incredible amount of love they all share.

You can listen to **Monica and Avram's full interview**, or read the highlights below.

Please note that Avram and Monica refer to Hunter syndrome as "MPS," which is an alternate name for the condition.

Interview highlights

Q: How would you describe each of your children, and in your eyes, what makes them special to both of you?

MONICA: Let's start with Kalel since he is the oldest. He is energetic, happy, and the sweetest child you will ever meet. He's very resilient and strong. Next is Logan, our middle child, who's eight. He is compassionate, extremely smart, and very loving. And then we have our littlest, Anaya, who is one and she is the sweetest, funniest little girl you will meet. She has such a great bond with her brothers already.

AVRAM: We call Kalel the **Sour Patch Kid** because first he's sour, and then he's sweet. He gets a little aggressive sometimes, but he does it for a good laugh. He's not doing it maliciously. Logan is an amazing kid, because he's the one that understands and is able to cope with all of the crazy chaotic stuff that Kalel does. And he's always the reminder that keeps the bonds strong. Then Anaya is our toughest little cookie. She gets teased by both her brothers and does it with a smile on her face. So that's our little family.

Q: When Kalel was diagnosed, how did you go about explaining the condition to Logan?

MONICA: It was very tough. Kalel was three and a half when he was diagnosed. So, Logan was two. They're a year and a half apart. It was difficult to explain it to him. He would ask, "Why does Kalel have to go to the hospital, is he going to have to go to the hospital forever?" We explained to him that Kalel was sick, he had to go to the hospital to get medicine, and that we were trying everything that we could so that one day, he wouldn't have to go to the hospital.

Logan would come with us to the hospital. He would sometimes cry, but we explained to him that it was going to help Kalel. And although he was very

young, he was understanding the concept. We've been getting through it as best as we could and just go explaining as he is able to understand.

AVRAM: I think since Kalel's diagnosis, Logan has been there every step of the way. We didn't hide much. In fact, at every presentation we've ever done for the MPS SuperHero Foundation, **our nonprofit organization we created after Kalel was diagnosed**, after both Monica and I speak, Logan gets on the microphone, and he ends our presentation with "Please help me save my brother's life." It has been very impactful. A lot of the times we received so much hope and I honestly feel like Logan had a big part in all of that.

But it's hard for him. I think the biggest obstacle that he faces is seeing all his peers, his cousins, and their siblings, and the relationship with each sibling. And he never had that opportunity.



“ Logan’s relationship with Kalel was completely different from the norm. He was aware of it when he was very young. —Avram

MONICA: I remember shortly after we brought Anaya home. He was holding her and he was kissing her. Logan said, “Mom, does she have MPS?” And I said, “No, baby, she doesn’t.” And he’s like, “Mom, you promise?” He was so excited to know that he had a sibling that was not diagnosed with MPS. And that was a crazy moment for us as well.

Q: As you mentioned for Logan, it's tough for him because he sees that his cousins have very different relationships with their siblings. What is it like for Logan at school?

AVRAM: One of the biggest decisions we thought long and hard about was if we wanted to separate them. Both Logan and Kalel got accepted into a charter school and we were excited. About 3 years ago, Kalel went in for one day, and halfway through the day, we got a call saying he needs a diaper change. We sat down with the principal that same day, and we realized that this wasn't going to be the right school for his needs.

We had to make a decision. Do we leave Logan in that school? Or do we take him along with Kalel wherever the next school is? We decided to ask Logan, and I kid you not, his response was that "I want to go to school with Kalel. Because if somebody bullies him or treats him bad, he's not going to be able to tell us."

I think maybe that's what we wanted to hear, but then we recently went to an MPS conference. We got to talk to a lot of siblings that were in the same situation just years ahead. We even spoke with some of the parents.



They said their bond is not going to be broken. Don't hinder Logan's academics because of what you guys actually want.
—Avram

After that conference, we decided to ask Logan again and be as transparent as possible. We explained that the academics at the new school was a better program, and all his cousins would be there as well. We let him know that Monica and I were going to do our best to find the right school for Kalel. After we explained it all, Logan said he was okay with going to a different school

than Kalel. So we signed them up and this is the first year they're going to separate schools.

Logan has to create his own identity. And last year, he didn't have that. He was Kalel's little brother. Of course, his classmates knew him by Logan. And eventually everybody learned his name, but he was always Kalel's little brother, and Kalel's famous at every school he goes to.

Q: What's Kalel's relationship like with both siblings?

MONICA: Kalel loves Logan. I always tell Logan, you are his favorite person in the world. Anytime that we go to the hospital and get a toy from the treasure chest, he asks, "Can I get one for Logan?" When he comes home, that is the first person that he asks for. He loves to play with him. He loves to push him too, because he likes his reactions. But he absolutely loves him. He hugs him and kisses him and is always talking about him. That's been since Kalel was a baby. We have a picture of Logan and Kalel at the hospital when Kalel was a year and a half old, and he's holding Logan. The way that he was looking at him is the same way.

Logan is in love with Anaya. He wants to hug her and kiss her and carry her. He has this thing that he plays with her since she was born. He always would say, "Booga booga roar!" And now Anaya responds with "Roar!" He has an amazing bond with both of them and he adores them so much.

Q: As Anaya gets older, do you two feel prepared to start having those conversations with her that Kalel has MPS and he's a little different than the other kids?

MONICA: I don't think I have really thought about how we're going to explain it to her. In my mind, I figured it'd be a little bit easier, because she was born when Kalel was already diagnosed. Compared to Logan, it was life-changing

because we were home all the time with both of them. Then our lives changed when Kalel was going to the hospital. A lot changed when Logan was born versus Anaya being born, and this is our life. I feel like this is all she knows and all she's going to know.

AVRAM: Yeah, that makes sense, because Logan had to witness the transition that we're going through versus Anaya growing up this way. I feel like the conversation would be a little bit easier too because she's already witnessing firsthand how it is.



Our biggest takeaway is that there's going to be a stronger bond between Logan and Anaya. Because they will be the only ones that truly understand each other in dealing with a sibling with MPS.

—Avram

Not real patients.

AVRAM: So hopefully, when that time does come, I'm sure she's going to have a lot of questions and we'll answer them as transparently as possible, just like we've done with Logan. But at least this time, we'll have a third person there to help describe it in a way that a sibling would understand.

The easy part is knowing there's something wrong. The hard part is explaining how to cherish the moments that we have, because we don't know how long it's going to last. That part alone is going to be the toughest conversation to have.

Q: How do you give attention to Kalel without it seeming like you're showing favoritism?

MONICA: The way that I tried to explain it for Logan is that every child is different, and every child needs different things. Kalel may need more attention while he's eating or while he's doing schoolwork or something, whereas Logan

is more independent. I try to redirect his thoughts to be grateful for the blessing that he is a typical child, and he is able to do all these things.

I remember when Logan was younger, before even starting school, one day he said, “I want to have MPS.” That broke my heart. I explained to him that Kalel has MPS and maybe he sees the treatment as fun because Kalel gets to play, but he’s not thinking about all the other things he has to go through. Kalel has to go to the hospital and go to many doctor’s appointments. I told him, “I don’t think you should wish you had MPS. Remember that you are Logan, and he is Kalel. And you guys are very different. And we’re going to give you each what you need as an individual.”

AVRAM: I have Logan on such a high pedestal. I expect so much of him that sometimes when he makes a comment like that, I—I have to really think about what I’m going to say next. I get frustrated hearing something like that.



It’s a learning process. It’s tough, but we look at every situation differently, because maybe the last time Logan didn’t grasp what we were trying to tell him.
—Avram

Q: How do you balance all your children’s activities, especially when they could potentially coincide with Kalel’s appointments or anything that’s going on with him?

MONICA: To the best of our ability, we try to coordinate so that things don’t fall on the same day or at the same time. So that way we can give our full attention to each individual child, depending on their needs. There are times when something may fall at the same time. Fortunately, for the most part, we’re able to coordinate so that we can all attend. As a family, we always try to like stick together, especially for games and those type of things. There were a few times where I

was able to take my niece with us. I asked her to go for a walk with Kalel while I watch Logan's game. She'll take him to the playground, and then he'll come back to cheer on Logan, or he'll try to run on the field and give everyone high-five. We try as much as we can to do everything as a family. Even though it's a lot more difficult to do so, it's our life. Our life is not easy, but we try to embrace it to the best of our ability.

AVRAM: We've dedicated a medicine day for Kalel, so we never schedule anything during that time. If something pops up and we have no control over it, then it is what it is.

MONICA: We've always really tried hard to make it a fun day for him. We also have tried to give Logan a "Logan Day." Either Avram or I will take him out to do something fun, and the other parent stays back with Kalel and Anaya. I think that has really helped Logan a lot because he understands there are times that we have to fully focus on Kalel, but we also have time where we fully focus on him.



We hold each other accountable for being the best parents we can be. I have a really great partner. Monica is the real rock. She makes things a lot easier for me.

—Avram



What tips or suggestions would you give other parents who may be going through a similar situation?

MONICA: Try to do the best job that you possibly can. Every family is different. And you don't have to be like anyone else. Be whatever you want to be. You have to find a way to be happy, even when things are rough. Always try to count your blessings.



What helps us through the hard times is refocusing our thoughts on the reasons why we are grateful rather than focusing on whatever the burden is at the moment.
—Monica

AVRAM: You have your kids, and then you have Kalel, Logan, and Anaya. They are each an individual person, and yet they are also a group of kids, right? You have to learn to differentiate at times and separate them from the group of kids. Remember that Logan is his own person, and he needs his one-on-ones, and Anaya is her own person, and she needs her one-on-one time. And the same thing for Kalel. There's no right or wrong way. I feel like because this is uncharted territory for most families, it's not of the norm. It's not typical. You're going to be different. You're going to stand out. Make sure that you're happy when you're doing it.

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