

Emily's RSV Story

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The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.

On February 22, the coalition released a new video, [Emily's RSV Story](#). Emily Lang lost her daughter to RSV in November 2021. Her way of grieving – as she explains it – is to advocate for greater awareness about RSV in hopes that other families will not have to endure what she did. Emily is incredibly brave, and we are so grateful for her willingness to share Presley's story to help other families understand how serious RSV can be.

The text from the video follows. Please feel free to share this video with your networks.



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“This is Presley’s bunny. It has a G tube and oxygen because she had a G tube and oxygen. She loved her bunnies. I’m Emily Lang. I am the mother of Presley Meeks, who passed away on November 26, 2021.”



This is Presley’s bunny. It has a G tube and oxygen because she had a G tube and oxygen. She loved her bunnies. I’m Emily Lang. I am the mother of Presley Meeks, who passed away on November 26, 2021. When Presley first got sick. It was fast. We know that she had a chest compression where it was like her lungs were going inside her ribs. And, that’s how we know that something was definitely wrong. We actually rushed to the hospital, and I said, “My baby is not breathing.” Okay? She was at 56%, her oxygen levels. They tested her for rhinovirus, RSV, and COVID. And at that point, they determined it was RSV. One of my friend’s babies actually gave Presley it [RSV]. They were having a play date. And, her baby was, of course, playing with Presley’s toys. And Presley touched her toys.

She was on a bunch of different machines. It was one day, she was on a normal ventilator. And then next day, we had to put her on a different ventilator. And then, at night, we’d have to be on this ventilator. And they were doing everything possible to keep her going. One morning I woke up, and I noticed there were about two new machines in the room, and I was like, What’s going on? And the nurse, I looked over at the nurse, and she was begging my

daughter, trying to keep her going.

“And I called my parents, and I said, “you guys need to get here soon.” Like, she’s not okay. She’s not going to make it. We need to let her go. On November 26, Presley passed away peacefully in my arms. Grief, it comes in a wave.”

And I called my parents, and I said, “you guys need to get here soon.” Like, she’s not okay. She’s not going to make it. We need to let her go. On November 26, Presley passed away peacefully in my arms. Grief, it comes in a wave.



“My way of grieving is to advocate and to spread awareness of RSV. I just feel like it’s important for people to know because I didn’t know what RSV really was until I went through having to lose my daughter.”

Some days I’m okay. And some days, I struggle a lot. My way of grieving is to advocate and to spread awareness of RSV. I just feel like it’s important for people to know because I didn’t know what RSV really was until I went through having to lose my daughter.

Disclosure: No relevant disclosures noted

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National Coalition for Infant Health Values (SANE)

Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

Access. Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

Nutrition. Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

Equality. Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.

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