Special Needs Lawyer Christine Matus Speaks With The E.WE Foundation Co-Founder Sarita Edwards

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Toms River, New Jersey -- Recently, Christine Matus, Esq., founding attorney of The Matus Law Group, had an insightful conversation with Sarita Edwards, co-founder of The E.WE Foundation, a 501(c)(3) healthcare advocacy organization supporting families affected by Edwards Syndrome. The foundation was started by Ms. Edwards and her husband, Kareem, after their son Elijah Wayne was prenatally diagnosed with Full Trisomy 18, or Edwards Syndrome.

Ms. Matus, a staunch advocate for special needs family and an NJ special needs lawyer, sat down with Ms. Edwards via Zoom to discuss the foundation, how it got started, and how they envision their future. She asked Ms. Edwards to give a bit of background into the ?why? of their foundation.

?I?m a wife and a mom to four boys and one girl. When Elijah was prenatally diagnosed with Trisomy 18, a rare condition, I left the corporate world to help care for Elijah. Our experiences enabled us to support other families going through the same thing. This became The E.WE Foundation.?

Because Trisomy 18 was considered ?incompatible with life? and consequently terminal, it left the Edwards family with little in the way of medical resources or any specialty care services. They left the hospital with no life-sustaining options but Hospice Care. But then their son Elijah started to thrive and grow. And they realized that there was more to be hopeful for than they had been led to believe. About two years into their journey, they wanted to help other families in ways that they had wanted help themselves.

?Our initial goal was to be end-of-life support and bereavement support, being that most people were being told that their child was going to pass away. We wanted to connect them with a Hospice team and help them with the burial and with finances if they didn?t have insurance,? she said. ?But now the foundation has evolved and has added legislative advocacy. We were able to sit down with a few members of Congress to share our journey, asking for support with bills that could create better outcomes for families with rare diseases like ours. That has turned into an education platform where we want to continue to raise awareness and bring exposure to diversity and inclusion for special needs kids.?

Today, the foundation is going strong, with many plans for the future. Ms. Edwards is starting a research project looking at the value of genetic and genomic testing in newborns in the hopes that different traits can be identified early to address them earlier. She says that the foundation is available for families who want guidance, support, or to begin learning about Edwards Syndrome.

?We hope that families would want to connect with us when they get the diagnosis so we can start our support right then,? she said.

For families who want more information regarding Edwards Syndrome or the work of The E.WE Foundation, there is a contact form on their website at https://theewefoundation.org/.

As for Elijah, he is a happy, healthy three-year-old and attends a program for special needs kids. Readers can follow him on his blog also available on the EWE foundation website.

Learn more about The Matus Law Group and their work with special needs families at https://matuslaw.com/special-needs-trust-attorney/

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The Matus Law Group is an experienced team of attorneys who can help you and your family plan for life, protect and care for loved ones with special needs, cope effectively with disability and death, and preserve inheritances for future generations.

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