

## **LKNFEST to Raise Awareness of Vanishing White Matter Disease a Very Rare, Terminal Brain Disease**



*VWM disease is a type of Leukodystrophy. Ella Rose is 1 of 300 in the world diagnosed. Ella, her 12-year-old brother, mom and dad live in Huntersville. She is the only one in NC with VWM.*

**MOORESVILLE, N.C. - Jan. 18, 2022 - [PRLog](#)** -- While casting for our **Matilda Jane, Mommy and Me Runway** show coming to **LKNFEST** on June 11, 2022 at the **Charles Mack Citizen Center** in **Mooreville, NC**, there was one Mother/Daughter model application that stopped us in our tracks.

"My five-year-old daughter has a rare terminal brain disease and has never walked unassisted. Ella uses her little red walker to get around and has a love for fashion and makeup. She would be honored to do this, and I would love to experience this with her. She is truly a blessing and is my hero. I'm in awe of her daily and she touches the lives of everyone she meets. She's truly remarkable. If selected, I would just need to make sure she can get her walker through the terrain at your location. Thank you. ?", wrote **Heather McKee**, accompanied by photos of herself and her daughter.

Event and show producer, Tammy Domenick and Matilda Jane Representative, Kimberly Sova knew right there that **Ella Rose** and **Heather** were going to walk in the **Matilda Jane Runway Show** and that they wanted to do all they could to make it amazingly special for the entire McKee family. "Time is precious, and we were not going to make them wait to know if they had been cast in the show", said Tammy Domenick. "Ella Rose and her family face uncertainty daily, and the feeling of not knowing what's next must be incredibly hard to bear. If I could relieve just an ounce of their wondering, I knew I had to," added Kimberly Sova.

Through more conversations with Heather, we became aware of just how rare Ella Rose's disease is. Leukodystrophies are a group of rare, progressive, metabolic, genetic diseases that affect the brain, spinal cord and often the peripheral nerves. There are 50 different types of leukodystrophies. Each type of leukodystrophy is caused by a specific gene abnormality that leads to abnormal development or destruction of the white matter (myelin sheath) of the brain. Vanishing White Matter disease is Ella's type of Leukodystrophy. In layman's terms, Ella needs a miracle as she was only given a few short years to live. She has a genetic disease that is destroying or will destroy the part of her brain that controls function and doctors cannot tell how rapidly this disease will take control of her tiny little body. Her motor skills, speech, hearing, vision, swallowing, etc., will all slowly begin to deteriorate, with the very raw possibility

of ultimately taking Ella's life. There are only six hospitals (Ella and her family travel to the Children's Hospital of Philadelphia) within the United States that specialize in her treatment and most often doctors have never heard of this disease. Currently there is no cure or treatment plans for Vanishing White Matter disease and because of that all funding for a cure or medical care is privately funding or at the expense of families affected. The strength of this Mom and family inspires us and leaves us in awe. When asked how we could assist, she asked us to "help get the word out about the disease and Ella", so that is what we plan to do!

On the **January 29, 2022**, LKNFEST will be livestreaming the announcement of Ella Rose rocking our runway, from our **Girls' Day Out** event taking place at the **Aloft Mooresville**, from **12 pm to 6 pm**. We will be presenting Heather and Ella Rose a Gift Basket to brighten their day, along with a special balloon bouquet in Ella Rose's favorite colors from our sponsor **Lakeside Balloons!**

If anyone would like to contribute a gift item or gift card to the Gift Basket, please email [info@lknfest.com](mailto:info@lknfest.com); anything for Ella Rose, her Mom or the family as a whole would be greatly appreciated.

If anyone with a brick-and-mortar location is willing to place a poster in your window, please e-mail [info@lknfest.com](mailto:info@lknfest.com).

If you would like to donate to Ella Rose directly to help offset the weekly medical expenses you may do so through her GoFundMe at <https://www.gofundme.com/f/v39m2v-a-miracle-for-ella-rose>.

We ask everyone to please share Ella's story on social media. Follow both her Instagram and Facebook @AMiracleForEllaRose.

**Share. Share. Share. Ella's doctors strongly encouraged the family to spread the word in hope of more research launched by doctors and pharmaceutical companies looking to find a cure.**

Any help in making Vanishing White Matter Disease and Leukodystrophy known would be greatly appreciated by Ella's family.

We are so thrilled to show this very special, sweet girl and her family an amazing time on both the January 29, 2022 and at LKNFEST this June; but more importantly to show them that they are not alone in their fight.

LKNFEST was created to shine a light on our amazing local businesses and community and we can't think of a better way for us to show off just how incredible the people here in the Lake Norman and Charlotte area are than supporting this family.

For more information on LKNFEST or the Girls' Day Out, Sip n' Shop event series, please visit <https://www.lknfest.com> or email [info@lknfest.com](mailto:info@lknfest.com).

#### **Media Contact**

LKNFEST

[tammy@lknfest.com](mailto:tammy@lknfest.com)

332-223-5220

--- End ---

Source            LKNFEST

City/Town      Mooresville  
State/Province    North Carolina  
Country        United States  
Industry        [Event](#)  
Tags            [Community](#)  
Link            <https://prlog.org/12901462>



Scan this QR Code with your SmartPhone to-  
\* Read this news online  
\* Contact author  
\* Bookmark or share online