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# Reagann's Rowdy Day

MAY 23RD 2013 BY DEE LOFLIN

Reagann's Rowdy Day

Written by  
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**Charleston, Missouri** – Reagann is the 4 year old daughter of Joe and BJ Duenne of Charleston, Missouri. She has a very rare disease called ROHHAD Syndrome. Diagnosing this disease was difficult and you would understand why it's called ROHHAD as the real name is Rapid Onset Obesity with Hypothalamic Dysfunction, Hypoventilation and Autonomic Dysregulation. What a mouthful for such a little girl. There are less than 100 children worldwide with this disease.

There is no treatment beyond experimental and there is no cure. On top of that doctors do not even know the source of the disease. Symptoms vary for each child and can begin with rapid onset of obesity in the first 2-4 years of life, followed by impairment of the nervous system and inevitably reduced lung function leaving children unable to breathe without the use of a ventilator.

Reagann is a strong willed little girl who is about to take a journey into the unknown. She will undergo experimental treatment of high dose chemotherapy on June 7<sup>th</sup> at Johns Hopkins in Baltimore, Maryland. Her immune system will be destroyed. Her family will live there approximately 3 months while her immune system is rebooted and hopefully resistant to the disease.

This rare treatment has been performed on two other children in the world, successfully treating several symptoms of ROHHAD. Our thoughts and prayers are with this family during this difficult time and we hope a cure is close at hand.

With all that they have suffered and the expenses are mounting, the community has once again come to the aid of their fellow American. Like the helping hands in Oklahoma, the citizens of East Prairie and Charleston are here to help.

**On June 1<sup>st</sup> from 1 – 4 p.m. “REAGANN’S ROWDY DAY”** event will be held at the East Prairie Main Parking Lot. They will have bounce houses, face painting, several carnival themed games for kids, a 50/50 raffle, a raffle for a Ruger 10/22 w/max laser gun, other raffles, and prizes.

The High School cheerleaders have donated their time to perform a cheer camp. They will perform around 3 p.m. KFVS12 will be there with some of their employees and their Live Truck to show off and see how it works. The Smoke Company will be serving their amazing BBQ and Randy Cook’s Snow Cone Truck will be selling yummiie treats. The Girl Scouts will have a bake sale. SAR will be showing off their dogs and search equipment and country singer Logan Toon will be performing around 1:30 p.m.

This will be an awesome afternoon! If you would like more information, please call Kristen Shankle at 573-233-5235 or email her at [Kristen\\_shankle@yahoo.com](mailto:Kristen_shankle@yahoo.com).

Hope Anchors the Soul, Hebrews 6:19

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