

JESSOP FAMILY

KALAMITY BENEFIT CONCERT

PKAN

All 3 of the Jessop kids have Pantothenate kinase associated neurodegeneration (PKAN,) a rare neurologic disease. There is no cure or medications that doctors can prescribe for this disease. There is a trial treatment available for this disease that is basically the family's last chance but it's so expensive. Their oldest son, Aaron who is 3, is progressing fast and they want to try this treatment for him but need the finances to make it happen. Their 4 year old twin daughters, Angie and Aubrey are not developing like a normal kid their age and it will only get worse. Please come out to support and donate to this beautiful family on this one night dedicated to them!



JESSOP WEDNESDAY
FEBRUARY 28TH, 2018

3

at Pine View High School

6:00 pm Bake Sale and
Hungry Howies Dinner

7:00 pm Kalamity and
Vault Family Show

SUHBA Members,

The following information was sent to us by a SUHBA member who has requested we send this notification out in hopes of helping the Jessop family of Prime Excavating (SUHBA member). Our thoughts are with family and please consider helping with the fundraiser scheduled for next Wednesday, February 28th. Please read the following information and the attached flyer for more details. Thank you.

You may know Lester Jessop of Prime Excavating and know what a great guy he is. But what a lot of people don't know is the struggles he's been dealing with, with his family. His three kids, 9 year old Daron and 4 year old twins Aubrey and Angie have a rare neurologic disease. It's called PKAN (Pantothenate Kinase Associated Neurodegeneration). To put it simply, people with PKAN lack a chemical necessary to metabolize a vitamin in the brain. Without normal levels of this metabolite, part of the brain degenerates, causing severe problems with walking, coordination, vision, speech, and swallowing. The illness is particularly cruel in childhood, when uncontrollable twisting movements can be extreme, causing pain and even bone fractures. Awareness is not affected, making the suffering imposed by the disease especially poignant. Many children with PKAN die before the age of 10. Imagine being faced with not only possibly losing 1 kid but all 3 to this horrible disease.

There is no cure. There is a foundation that has identified a compound that they believe may change the course of this terrible disease. They have had huge breakthroughs in testing the compound on human cells and mice and received amazing results. They have met with the FDA and the FDA is supportive of the foundations plan to move the compound quickly into humans. The price of the compound is extremely expensive. For a family that has to have it for all 3 of their kids to live is astronomical.

Family and friends, along with Kalamity dance group are planning a fundraiser for the Jessop family. We are trying to raise as much money as possible for the family. Please donate what you can. Every little bit helps. Attached is the flyer with all the information for the concert. All proceeds will go to the Jessop family.

You can also donate on Facebook through Kalamity Dance page. Direct message owner Tia Stokes and you can donate through your Facebook app on your phone!

<https://www.facebook.com/kalamity.dance.7>

Or you can donate on Go Fund Me

www.gofundme.com/give-so-they-can-live