Hi! We are the Erbes family; Mike (dad), Sara (mom), Landon (big brother), Lillian (big sister) and Grayson (our cancer warrior). We are very thankful for all of YOU; the support from Dance Marathon has been amazing. Your dedication and love for kids, like Grayson, is appreciated and doesn't go unnoticed.

Grayson's journey is one that occurs in 1 in a million people worldwide. In early March 2016, at just 10 months old, we noticed that Grayson's eyes started moving back and forth in a chaotic rapid manner. All you had to do was look at him for a moment, and you'd see them move quickly back and forth. We went to our pediatrician looking for answers and she referred us to an ophthalmologist. He ruled out a couple different things and confirmed there were no tumors behind his eyes, but we left his office without a diagnosis.

Grayson continued to decline rapidly over just a couple of weeks. Our happy baby became extremely fussy, hardly slept, wanted to be held all the time and wasn't eating much. We were on the search for answers, and we knew that if anything serious was wrong with him we wanted him to be treated in Iowa City. On Sunday March 20th, 2016 we headed to the U's ER department and after a short visit in the ER we were admitted. We weren't given a diagnosis, but just told that the doctor's would feel better if they could do some testing on Grayson to see what could be causing his eye movements.

The next day brought us a lot of testing and an introduction to a doctor in the pediatric neurology department. After many tests and consulting with other doctors, on Tuesday March 22nd, his neurologist diagnosed Grayson with Opsoclonus-Myoclonus-Ataxia Syndrome (OMAS). OMAS is a rare neurological disorder in which the immune system views the brain as a foreign body and therefore attacks it, often times resulting in brain damage. There is no cure for OMAS. The eye movements we had been seeing, were visible signs of Grayson's brain being attacked. 50% of OMAS cases are a result of a Neuroblastoma tumor; so we were referred the pediatric oncology department. I remember, like it was yesterday, hearing the words "I'm going to refer you to the oncology department." It was a punch to the gut. There I was standing in the play room on 2J, with my baby boy, being told we needed to meet with an oncologist.

That afternoon we met with the oncologist, who explained that a small percentage (2-3%) of Neuroblastoma tumors can be a cause of OMAS. She scheduled Grayson for a CT scan to see if he had a tumor. On Thursday March 24th, 2016 we were told that a mass was found in between two vertebrae

located just above one of Grayson's kidney. Being told your child has "a mass" was THE worst moment of our lives. Immediately you go thru scenarios in your mind; "what if this" or "what if that." The mass needed to be removed; so on Thursday April 7th we handed Grayson over to the surgical team for a 7 hour surgery. The surgeon was able to remove 95% of his tumor and he placed a port for any future treatments Grayson may have. The pathology report confirmed that Grayson had non-amplified, Stage 2 Low Risk Neuroblastoma. Based upon the pathology report, Grayson's treatment plan was put together.

Grayson's birthday is April 10th and we wanted so badly to be able to celebrate at home, but we weren't released in time. He celebrated his 1st birthday in 3J. The nurses were wonderful and made him cards and decorated his room with them. They helped make his day extra special.

In less than a year, Grayson has had 3 inpatient hospital stays, surgery, a port placement, numerous blood draws, various testing; including MRI's, a CT scan, MIBG scans, x-rays, echocardiograms, lumbar puncture, bone marrow aspiration and ultrasounds. His treatment has included Dexamethasone, Rituxan, ACTH, Cytoxan and IVIg. Today, Grayson is a VERY active 21 month year old. He will have his 6th, and final, round of chemo on Wednesday February 15th. He will then be monitored with MRI's every few months to make sure nothing scary pops back up. Grayson's Neuroblastoma has forever changed his immune system; so we will continue treatment for his OMAS until we can kick it into remission.

Dance Marathon has been such a blessing to our family over these past 9 months. The students we have encountered have been amazing and kind. Our family rep has been so sweet; visiting us during treatments, sending us letters and care packages. Thank you to the students who work so hard to raise money for kids, like Grayson. Your hard work has given us RX co-pay assistance, medical supplies for use at home, a gift card to help with Christmas expenses, free & reduced parking, gift certificates to area restaurants and AWESOME family outings. We are forever grateful to Dance Marathon and all that YOU do.

FTK!
The Erbes Family