



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

My daughter Nora McConathy was only 10 months old when she was diagnosed with ETMR. She fought for 4 months. Unfortunately she lost to this childhood cancer and went to Heaven on 2/19/22.

I took her to the ER in the middle of Sept at 9 months old for right sided facial weakness. She was diagnosed with Bells Palsy without any imaging (I am actually a nurse practitioner in hem/onc) so I was concerned but the neurologist convinced me that's all it was.

Fast forward 6 weeks; she is lethargic, not eating, quit babbling, was no longer able to walk, seemed so unsteady and had bilateral facial palsy.

We went back to the ER. Admitted for weight loss, dehydration, and loss of milestones. CT of her head showed possible mild infection around her bone in her ear (she had an ear infection for 6 weeks off and on). They were treating her with IV antibiotics and planned on discharge. I was adamant that she needed an MRI. Next day, she had an MRI and was found to have multiple brain and spinal mets.

Laminectomy done on 11/3 to get a biopsy and showed ETMR. Port and G-tube placed on 11/15. She was put in the ETMR ONE registry.

Cycle 1 chemo started 11/16 with high doses of methotrexate, cyclofosfamide, vincristine, cisplatin and etoposide. She received 3 cycles of this regimen with a drastic clinical response. But she did develop severe hydrocephalus leading to the need for emergency shunt placement. She also had an ommaya placed at the same time.

She then started stem cell harvest for the next sequence of tandem high dose chemo with stem cell rescue but she developed a blood infection during this time and contracted covid. Her symptoms were minimal but her treatment was delayed.

My husband and I had to take turns taking off work. We still had the same bills and now hospital bills. It was a struggle to take care of our older son. We had to watch our daughter be poked and prodded day in and day out. We lived in the hospital for nearly the whole 4 months she received treatment.

No child or family should have to go through this. Watching my daughter suffer due to no treatment protocol for her type of cancer was devastating. Our daughter had metastatic ETMR with spinal cord involvement. It is so rare; there are no treatment protocols. The average age is 0-5 years old. It is extremely aggressive. Prognosis is extremely poor. Only 10 percent live past 12 months of diagnosis. We have to do better. We need better treatment for our BABIES. Our daughter was 14 months old when she died. She went through more in her life than most 80 year old people.

It has been formally estimated in 2022 that over 15,600 children will be diagnosed with childhood cancer, and 1,780 will die of the disease in the United States. Further, brain cancers are the second most common form of childhood cancer, accounting for over 20% of all cases.

By signing this petition, you will be sending a compelling message to Congress to pass federal laws that mandate relevant federal institutions and agencies to increase their spending on childhood cancer research from 4% to 8%.

These children are our future and they deserve the best chance at beating cancer without such harsh treatment and devastating side effects. They are our world. Let's help them succeed!

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