



On Tuesday March 23, 2021, at four years old, our son Rourke complained that his foot hurt and the next day he wouldn't even walk on it. A visit to the orthopedic doctor showed mild swelling in x-rays and all his lab work came back low. Rourke's hemoglobin was about 5 (normal range is 10-12) and he was admitted for a bone marrow aspiration/biopsy. This confirmed that Rourke had CNS3 B-cell ALL (Acute Lymphoblastic Leukemia). Testing continued, then on Monday March 29, 2021, a port was placed in Rourke's chest to do blood draws, for him to receive treatments and anything else he would need through an IV.

On March 30, 2021, Rourke started his "28 days". This consisted of 8 different chemo drugs given on specific days mapped out specifically for his CNS3 diagnosis. First, he received Vincristine which can cause numbness/pain in the hands and feet and constipation. The next one was Daunorubicin which changes

the color of a person's urine, cause mouth sores, can lead to cardiac failure, can lower blood count, cause nausea being treated with zofran and hair loss. This was just the beginning of what seems will never end. Never being able to know our son will be ok. Never being able to feel certain of anything. Never being able to stop thinking.

The overall effects of cancer on our family are hard to put into words. Distress, along with psychological issues, PTSD, anger, frustration, loss of sleep, weight, appetite, and taste are just a few things we deal with daily. My husband lost his job because his company wasn't willing to work with our son's extensive treatment schedule. This is a huge burden financially on our family. So now on top of everything is the worry of how it all will be taken care of. Our other son shows signs of distress as well. Acting out, staying with other family members for days, weeks, or months while we are in the hospital. It is very apparent he feels neglected compared to our sick child. According to the International Journal of Hematologic Oncology, a significant number of children with cancer will experience cancer-related posttraumatic stress symptoms (PTSS) and disorder (PTSD), which can lead to long-term impairment.

My husband and I are constantly stressed and worried about every little thing. You can't live a normal life. You can't make plans. When will you have to rush to the emergency department? How long will the hospital stay last this time? How will my other son handle it? No one should have to go through what we and unfortunately so many other families are going through. Time, schedule, cost, treatment regimen, watching my son suffer. The list is so long, I could go on all day.

According to the United States Environmental Protection Agency Leukemia is the most common cancer in children under the age of 15, accounting for 30 percent of all childhood cancers. This petition can have a direct impact on lowering this percentage of childhood cancer by increasing federal funding for childhood cancer research. By collecting 12 million signatures with this petition, we can begin lobbying for raising childhood cancer research from 4% to 8%. In signing this petition, you are making a change possible that is so greatly needed.

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