

2014 Town of Babylon Supervisor's Cup Soccer Marathon



Taylor is a 12 years old girl who has been battling Neuro Degenerative Langerhans Cell Histiocytosis for over 3 years. She has gone through things no child should have to go through. In the past 4 years she has had numerous MRI's, x-rays, blood work, spinal taps, PET scans, surgery, a year of IV chemotherapy, oral chemo and now she will be starting a new chemo that we can

only hope stops the progression. Doctors do not know enough about this disease to have all of the answers.

Taylor was diagnosed with Neuro Degenerative Langerhans Cell Histiocytosis (LCH) that has caused a lesion on her brain as well as neuro degeneration to her cerebellum and brainstem. Histiocytosis is a rare life threatening disease that affects only 1 in 200,000 children. It is therefore considered "an orphan disease", so there is no government funded research for it. Many children are going undiagnosed for far too long and then it is too late for them. Taylor did a press conference a couple of years ago at the hospital for Rare Disease Awareness Day and in it she wrote "just because Histo is rare, it doesn't mean kids like me with Histo don't matter". She wishes that people knew about Histo and she is 100% correct. Since it is so rare (1 in 200,000 kids) it is very hard to diagnose and know what the "right" treatment plan is. This disease is also so rare that it is considered an "orphan disease" so it doesn't affect enough kids to warrant government funded research. Back to her story... Taylor has gone through 3 different regiments of IV chemotherapy since August 2010. In the past 3 years she has undergone over 100 intravenous chemotherapy treatments, two different oral chemotherapy pills that she took every day, a ton of MRI's, CT scans, constant blood tests, lumbar punctures, physical therapy, weekly doctors' appointments and she had a craniotomy this year to try to help the doctors figure out the best way to treat her. Since she has had so much chemo she will most likely also be getting IVIG infusions to help boost her immunoglobulin levels (infection fighters). The side effects of chemo are very tough on her body, we hate that she is going through this but she is very strong and resilient. She will eventually kick histio's a**, as Taylor says "Losing is not an option"....



Sally, who was diagnosed with Infant ALL Leukemia in July 2013 at the age of 10 months. This form of the Leukemia is very rare, only 90 cases are diagnosed a year in the United States. In addition, Sally's is a Mixed Lineage Leukemia (MLL) with a translocation of her (4;11) chromosome. Sally began treatment in July 2013 and is expected to receive intensive chemo for two years. After that, we will have to wait another year and a half to make sure her cancer does not relapse. This means we have to hold our breath until 2017 begins if everything goes to plan. Sadly, relapse rate is high in Infant Leukemia, which often leads to treatment involving a transplant, so the threat is a very real one for our little girl. Infant Leukemia is considered very high risk. Unlike Leukemia in older children which has an 85% survival rate, Infant Leukemia only sees a 47% survival rate. It is much harder to treat when diagnosed this early, especially with an MLL and requires more intensive chemotherapy treatment than what is typically used in older kids with the disease. Although we know Sally is getting the best treatment available, much of it is outdated and can cause serious life-long complications including heart damage and even failure. Kids with various cancers are all experiencing the same challenges regardless of their diagnosis. Although the treatment is killing the cancer, it is doing irreparable damage to children at the same time. This is why funding of pediatric cancer research is so badly needed. Dad, Mom, Thomas (7) and William (4) are determined for Sally to get through this and move on with her life. Please help by funding research for better treatments.



Dylan Beach is a 7 ½ year old second grader at St. James Elementary School who has been battling cancer for the past 5 years. On December 2, 2008, then a 2yr-old Dylan had emergency surgery to remove a large cancerous brain tumor. He

endured 6 months of intensive chemotherapy and stem cell rescue/transplant, spending weeks at a time at Schneider Children's Hospital in New Hyde Park. Dylan was in remission for nearly 3 years when a routine scan in March of 2012 revealed a recurrent tumor. He stayed in remission for another 19 months until another routine scan in November 2013 showed his tumor has returned again. Dylan had his tumor removed but the recurrence has necessitated additional treatment. Unfortunately Dylan's mom Amy was forced to take an unpaid leave of absence from her job to stay with Dylan while he undergoes treatment in Boston. As you can imagine this has put a financial strain on the family to make ends meet and cover his medical expenses.

Dylan plays dek hockey and lacrosse. He is an honorary teammate of the Hofstra Pride Men's Lacrosse team.