

#102 IMPORTANT – Personal Message from Heidi J. Moore

Dearest Advocates-

It is with a very heavy heart that I let you know that on Friday, we got confirmation from the oncologist that Jacob does have Acute Lymphoblastic Leukemia (ALL) - also known as Childhood Leukemia. As you can imagine, we continue to be devastated by this news. A dear friend of mine sent me an email stating – “Welcome to Holland” AGAIN. For those that know that wonderful poem, here is a link to read:

<http://www.ndsccenter.org/resources/package1.php>

This is the poem that gave us comfort when we found out over 10 years ago that Jacob was diagnosed with Down syndrome, excess water on the brain and severe heart defect during pregnancy and may not live through pregnancy. Now we are in a “new club”. Not one that we expected, given all the other medical issues Jacob has had over his last 9 yrs of life. We are still trying to understand what this all means, how we are going to cope, and most all dealing with this unexpected news for our entire family. We are especially concerned about Jared and how he will be affected by all of this.

Words can not express what we have been going through but I must say that we are overwhelmed by the amount of love, support and prayers we have received already. From the bottom of our hearts, THANK YOU!

I wanted to give you a summary of what is going to happen in the coming weeks/months. Obviously, this all can change depending on how Jacob reacts to the chemotherapy and his recovery but you know me.....I’m an engineer by heart and a planner so here we go-----

This Monday, we will be meeting with the Aflac Cancer Center to discuss Jacob’s treatment in the coming months and he will be admitted to the Scottish Rite Hospital in Atlanta. We know that we will be somewhere on the first floor (this is a dedicated cancer center for children during our long stays at the hospital).

On Tuesday at 7:30AM, Jacob is scheduled to go in the OR (operating Room) to have the following done: installation of an IV port directly in his chest (this is a way for the medical staff to have easy access to Jacob and it will stay in him during his entire treatment process), a spinal tap and a bone marrow biopsy and draw. Jacob will be in the hospital anywhere from another 4 days to 2 weeks depending on his reaction to the chemotherapy.

The good news (if you want to call it that) is that Jacob got the “good” leukemia. Hopefully, he will not have to be in the hospital as much for his chemotherapy and will be able to come home more often and go back to school.

The counselors have told us that the more we can have a “normal” life for Jacob- the better! We are going to try very hard for Jacob to continue to have interaction and support from everyone (when the doctors allow).

We have been told the “typically” time to treat this disease is 3 yrs. The intense chemotherapy will last for the next 9 months and then after that it will depend on Jacob’s body. We know that the power of prayer works, so let’s all pray that Jacob’s recovery is quick and he will be able to be pain free and live as much as a “normal” life as possible with all the love of his family and friends.

If you are interested, the following is a wonderful website that will probably give you more information than you care to know. The key is that you must keep your search to only what Jacob’s has been diagnosed with. Here it is:

<http://www.curesearch.org/articleprint.aspx?ArticleId=3163>

I know many of you have sent emails stating that you want to help via taking care of Jared, meals, whatever. Below is a link to help understand what we are going to be needing in the coming months/years:

http://www.curesearch.org/for_parents_and_families/newlydiagnosed/article.aspx?ArticleId=3119&StagId=1&TopicId=4&Level=1

I understand this is overwhelming to read---You can never imagine how hard it is type it! I’m crying right now as typing and listening to my motivation music CD that I made many years ago to help me during the rough times and keep me focused on advocating for Jacob and all the children with disabilities. My strength is first from God and then my awesome husband and then my family and friends. I/we will need you during these times. I know many of you understand my character and how hard it is for me to ask for help but God has put me on my knees. YES, we need help and YES, we will be asking for it.

To make future communication easier for us, if you are interested in knowing how Jacob is doing, see pictures, leave a message on the guestbook or just receive e-mail notification when the journal is updated, please go to

<http://www.caringbridge.org/visit/prayforjacobmoore>

This is how we will be able to communicate with you quickly and you will be able to do the same with us.

As for my advocacy efforts, this will have to be put on hold. My family and my precious Jacob need me more now than ever. I do not plan on sending out any advocacy newsletters for awhile and will not be conducting any consulting services as well. I

know many of you understand my anguish and how hard this is to even communicate. Please just keep Jacob and our entire family in your prayers during this time.

United- We Will Make a Difference!

Sincerely,

Heidi