

## **#130 Transition & NOW-COMP Waiver Conferences and Childhood Cancer Fundraiser**

Dearest Advocates:

Wanted to keep you informed of some upcoming events/conferences that you may be interested in next month.

**The FOCUS on Transition Conference** will be held on **Oct 27, 2012 at Mercer University**. I will be presenting on the NOW/COMP home and community based Medicaid waivers. In addition, many other presentations that families need to know about as their child with disabilities ages out of the public schools system. Pre-registration is required.

**October 19, 2012 - Participant (self) Direction Conference** for NOW/COMP home and community based Medicaid waivers. I know that many families have questions regarding these waivers and how to navigate the system as a participant directed employer. The Dept. of Behavioral Health and Developmental Disabilities (DBHDD) will be there to answer your questions!

Both flyers can be found on: <http://www.heidijmoore.com/events/index.php> Pre-registration is needed for both events.

### **I need your help - September is Pediatric Cancer Awareness month.**

Our lives changed forever on November 13, 2009. This is the day we received confirmation from Jacob's oncologist that he had Acute Lymphoblastic Leukemia (ALL) - also known as Childhood Leukemia. As you can imagine, we were devastated by this news especially given everything else Jacob has went through during his lifetime.

Jacob has been receiving chemotherapy for almost three years now and is into his FINAL YEAR of chemotherapy including chemo pills every day, chemo via his IV port once a month and spinal taps every 3 months. In addition to cancer treatment, Jacob also see's over 16 specialty doctors and 4 therapists on consistent basis! He is a very busy boy. An end of year treatment date is January 20, 2013 after a long 3.5 yrs of treatment and then another 5 years of monitoring to make sure the cancer does not come back. Jacob will be considered "cured of cancer" when he is 18 years!

Words cannot express what we have been going through but we must say that we are overwhelmed by the amount of love, support and prayers we have received at during this journey. I hope you will consider donating in honor of Jacob to help us find a cure for childhood cancer. No donation is too little and could help save a life!

To watch Jacob's first year Cancer Journey video, please go to:  
[www.youtube.com/watch?v=2GjPfmIZ76g](http://www.youtube.com/watch?v=2GjPfmIZ76g)

We had no idea that children with Down syndrome have a 1-95 ratio of having Leukemia (general population is 1-2,000). There has to be a reason why children with Down syndrome like Jacob are more inclined to have this disease and if we can find that link... We just might be able to find a cure for Leukemia! Because of the everyone's support, "Jumping for Jacob" (our birthday fundraiser we had on 1/9/11) has now contributed to a Childhood Cancer Research Grant for targeted treatment at the Northwestern University-Chicago campus for targeted therapy of Leukemia in patients with Down syndrome in honor of Jacob. The Rally Foundation is continuing to fund this research project this year due to the progress being made...PLEASE help us continue to fund this important research!

We want to continue our advocacy efforts and raise money for pediatric cancer research. Let's all work together to make sure NO CHILD goes through what Jacob has this last couple of years. We need to find a cure! Many thanks to all that support this cause with us.

***UNITED- WE WILL MAKE A DIFFERENCE. For those that donate, you will receive a ONE OF THE KIND picture of JACOB praying to remind you how you are making a difference in this world! Thank YOU!***

The money raised will go to directly to the Rally Foundation, a 501(c)(3) non-profit dedicated to raising funds to support childhood cancer research which is under-funded by at least \$30 million a year.

**Please donate today: [www.razoo.com/story/Rally-For-Jacob-1](http://www.razoo.com/story/Rally-For-Jacob-1)**

Thanks in advance for your support during this difficult time. I hope that next year will be easier for the Moore Family and I will be able to advocate, educate and help many families with disabilities (and cancer) in the future. Have a great evening.

*United- We Will Make a Difference!*

Heidi J. Moore

(Proud Mother to Jacob – 12 yrs old with Down syndrome and Leukemia and Jared- 10 years old with amazing spirit & love for his brother)

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If you would like to receive Jacob Moore's updates or post prayers, please go to:

<http://www.caringbridge.org/visit/prayforjacobmoore> or [www.teamjacob.org](http://www.teamjacob.org) . To watch Jacob's Cancer Journey video: [www.youtube.com/watch?v=2GjPfmIZ76g](http://www.youtube.com/watch?v=2GjPfmIZ76g)

For disability information and previous newsletters, please go to [www.heidijmoore.com](http://www.heidijmoore.com) .

*"Help The Children Now, So They Can Help Themselves Later!"*

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