

#120 Childhood Cancer Research Grant & Federal Medicaid Action Needed

Dearest Advocates:

On Sunday, January 9, 2011 (Jacob's actual birthday), we celebrated with a fundraiser at Monkey Joe's in Roswell, GA. Even though it was starting to snow, over 300 people came out to celebrate this big event with Jacob and our family. That night we raised over \$ 15,000. 100% of the money raised went 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.

Because of your support, the Rally Foundation announced today that it is contributing \$30,000 towards 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*. Below is the actual press release. Many thanks to all the wonderful people (family, friends, strangers, sponsors, etc) that were involved to make this reality. Don't you love the picture?

I do truly believe that there is a reason why God allowed Jacob to have cancer and how I justify it in my own mind is... he knows that Jacob (and everyone supporting him) will come together to make a difference for not only Jacob but the hundreds of children like him. There has to be a reason why children with Down syndrome experience a higher rate of being diagnosed with Leukemia than the general population.....

One in every 95 children with Down syndrome develops Leukemia, compared with one in every 2,000 children without Down syndrome!!!

If we can find that link and reason why....We might just fight the cure for ALL CHILDHOOD CANCER. At least that is what I pray about all the time. I truly believe that NO CHILD should have to go through what Jacob has this last 20 months but with your help.....We are going to find a cure! Thanks again for all your support this last 20 months as we are in the battle of our lives for Jacob. I hope that in the next year he will be more stable so I can get more involved with advocacy efforts for children and adults with disabilities.

In addition, below is information regarding advocacy needed regarding Federal Medicaid funding for home and community based services. This may and will impact ALL of us in the future since the majority of Medicaid funding comes from federal \$\$ not state. Please take a moment and get involved to make a difference.

United- We Will Make a Difference!

Heidi J. Moore

(Proud Mother to Jacob – 11 yrs old with Down syndrome and Leukemia and Jared- 9 years old with amazing spirit & love for his brother)

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Immediate Release

LOCAL EVENT HONORS CHILD FACING DOWN SYNDROME AND CANCER
***Jumping for Jacob* Contributes To \$30,000 Childhood Cancer Research Grant**

ATLANTA— June 30, 2011 -- Rally Foundation, a national non-profit organization committed to research to fight childhood cancer, announced it will be distributing \$30,000 to fund research at Northwestern University-Chicago Campus on the biology and targeted therapy of childhood Acute Lymphoblastic Leukemia (ALL) in patients with Down Syndrome.

Funding for this grant was made possible through *Jumping for Jacob*, a family fundraising event honoring 11-year-old Jacob Moore who has Down syndrome and is currently battling leukemia. Diagnosed in November 2009, Moore is a Rally Kid, a child who has fought or is fighting cancer, and is currently in the middle of his three and a half year treatment plan.

“Through the grant provided by Rally Foundation in conjunction with fundraising efforts from *Jumping for Jacob*, we are taking one step closer to understanding the link between Down Syndrome and ALL,” said Dr. John Crispino, the Rally-funded researcher at Northwestern University. “This research will lead to continued breakthroughs in successfully treating the disease in patients with Down syndrome and allow us to learn more about the varying effects of current treatments.”

Rally’s grant at Northwestern is a part of the collective \$700,000 in childhood cancer research grants made nationally this year. In its first five years, Rally has given more than \$2.2 million in grants across the country in its efforts to find better treatments with fewer long-term side effects. These grants support more than 50 projects nationwide that include young investigators awards, research nurses and fellowships. For every dollar Rally receives, 93 cents goes to support its mission, according to independently audited financials.

“Communities and families, such as Jacob’s, across the country have joined Rally in supporting the need for more research,” said Dean Crowe, Founder and CEO of Rally. “It is our hope that, one day soon, new and more effective research will eliminate all childhood cancer.”

For more information on Rally, visit www.rallyfoundation.org.

About Rally Foundation for Childhood Cancer Research

Rally Foundation, a national 501(c)(3) non-profit organization based in Atlanta, empowers volunteers across the country to raise awareness and funds for childhood cancer research to find better treatments with fewer long-term side effects and, ultimately, cures. Cancer is the number one disease killer of children, and its research is severely underfunded each year. For more information on Rally, visit RallyFoundation.org.



From: Georgia Council on Developmental Disabilities <gcdd@ciclt.net>

Sent: Tue, 05 Jul 2011 17:47:56 -0000 (UTC)

Subject: Medicaid Alert-Please Contact Your Senators & Congressman/woman

Dear People;

If you have been listening to the news at all lately, you are aware that various proposals are circulating to reduce spending in the federal budget. One of the areas that is under consideration is Medicaid. This is the federal program that supports the health care of women and children, and the program that funds home and community-based supports for people with disabilities. In Georgia, 288,700 people with disabilities receive health care through Medicaid, and 30,600 receive home and community based supports that are funded through the Medicaid program.

PLEASE take a minute to respond to this e-mail, and let our congressman know that we will not support reductions in the services that support our family members to live in the community and to have adequate health care coverage. The links below provide the contact information for Georgia's senators and representatives. A brief message follows. Let them know you are paying attention!

Thank you!

To identify your Senators, click on your state at

http://www.senate.gov/general/contact_information/senators_cfm.cf

To identify your Congressman/woman, go to <http://www.house.gov/> and enter your zip code. Some districts require a 9 digit zip code, which you can find at <http://zip4.usps.com/zip4/welcome.jsp>

The message is simple:

* Identify yourself and your home town, so the staffer you speak with will know you are a constituent who has the power to vote in your state/district.

* Tell the staff person how essential Medicaid is for people with developmental and other disabilities. Add that it is cost effective to provide home and community-based services rather than pay for people to live in a nursing home or other institution. There are better ways to balance the budget.

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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 . To watch Jacob's
Cancer Journey video: www.youtube.com/watch?v=2GjPfmIZ76g

For disability information and previous newsletters, please go to www.heidijmoore.com .

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

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