



ADVOCACY ALERT

May 1, 2009

Hello Everyone ~

Happy May Day! I don't know about you, but I've never known anybody who really ever celebrated May Day. I've seen pictures of children dressed beautifully with halos of spring flowers in their hair, holding ribbon streamers decorating a pole..... but since I didn't know the true meaning of this celebration it seemed impractical to do all that skipping in a circle. If I'm going to be skipping, I want to get some where and not just be going around in circles. Next Thursday, when I skip to Baton Rouge, I'm optimistic I'll be able to get some where. But, first things first.

I hope everyone got a chance to see the April 20th issue of *Newsweek*. Epilepsy made the front cover. "THE MYSTERY OF EPILEPSY Why we Must Find a Cure" made a national magazine cover story..... Now, that's some skipping. Jon Meacham, *Newsweek* Editor stated that, "readers hailed the April 20 cover story on epilepsy, a devastating, and often misunderstood, disorder. A teenager confessed to feeling "now more understood and most importantly, more normal." While others related tales of triumph and tragedy, all under-scored the need for increased funding and research. As for the stigma factor, one reader admitted to "only recently coming out of the closet"; while one mom said it best: "my daughter has more spunk and courage than a combat unit and she also happens to have epilepsy."" (Newsweek, May 4, 2009) Greg Grunberg, National spokesman for the Epilepsy Foundation whose son has epilepsy, also wrote a letter to the editor of *Newsweek* and mentioned his new campaign www.TalkAboutIt.org, a web site where stars like Jennifer Garner and John Mayer are encouraging people with epilepsy to be open about what they are going through. If we just "Talk About It", we can eliminate the mystery and the fear. (*Newsweek*, May 4, 2009)

Back to my own personal skipping.....May 7th I've planned a trip to Baton Rouge for "A Rally at the State Capitol". I will be visiting as many legislatures as they'll allow me to see and introduce myself as your representative. I want them to know that there are people in Louisiana with epilepsy, lots of people and those people can vote and do vote. Let them know that we are not just skipping in circles.....we are on a straight forward path.

Here's where I need your help. You are receiving this email to be informed about the Foundation's Advocacy. I would like to know if you would be interested in becoming more involved. My first desire would be to find people who are interested in being trained on advocacy, willing to write or call representatives or be a "region captain". It has been suggested to divide the state up in regions and have someone in each region that would be able to tell me the concerns of "their" area. This would be helpful when we meet with representatives from certain parishes to inform them about our issues. This would not be time consuming or over-whelming. We are in the beginning stages of developing a "grass-roots" group and are taking everything slowly. I attended a seminar on Advancing Advocacy this month and learned: The purpose of Advocacy is to inform, to get action and to win change. Advocacy is about educating others and, last by not least, three good reasons

to get involved: Service is not enough, government policies affect everyone and policymakers need YOUR EXPERTISE to make decisions.

I'm asking for your help! Don't spend your time skipping around in circles. Join me.... Let's all go in the same direction and make some progress in educating others about epilepsy. If you are interested in being more involved in our grass roots campaign or you would just like to talk to me about the level of participation, or if you would like to talk about anything at all, please contact me at amy@epilepsylouisiana.org .

I look forward to hearing from you soon.

Until next month,

Sincerely,

Amy Nichols
Skipping you straight