

July 19, 2007

Today we are attempting to make a decision that should be made sooner than later. Yesterday Gregory and I were watching Good Morning America together as he ate some toast. He's trying to eat a little something every 2 hours so that means he needs to wake early. Possibly it was divine intervention yesterday for him to see this news story while munching on his breakfast. On the program there was a special about a drug called Terceva, a chemotherapy drug said to "possibly" give up to 12 weeks longer in terminally ill patients, specifically with metastatic lung disease. Immediately we lit up and I got on the phone calling doctors, nurses, insurance companies etc. to see if we could get the drug, which is still in clinical trials and not yet FDA approved, and if the insurance company would pay for it. (that's what the GMA news story was about: some insurance companies not paying for non-FDA approved medicines) Today we have the approval from Dr. MacArthur that if Gregory wishes to try this medication he can do so but it is not without risk. Taking the chemo drug might shorten his time, 10-15% chance. It may also lengthen his life by weeks or months but it might not lengthen a good quality of life. As you can imagine the decision is agonizing. Please pray for him to make a decision that he is at peace with no regrets.

All other blood work looks test book nearly perfect. His psyche is amazing. We talked earlier about things no parent wishes to ever have to talk to their child about and we are blessed to know his wishes so he is living his days with a lot of peace. That give me peace. Our long talks give me peace. Every time I hold him in my arms I am at peace. Every kiss on the forehead, every time I look into his eyes, I have a sense of peace because he is here with me now and I cherish him dearly. This is not to say that I am not without anger. Believe me, there is plenty of anger, confusion, frustration, and more anger as I'm sure all of you are experiencing also. There is no answer to the "Why's?" or the "How's?". I am no longer searching for those questions to be answered because they would drain my energy that needs to flow towards Gregory in a positive manner. We, again, are taking this day by day, hour by hour, cherishing.

Thanks so much to everyone for writing into Gregory's Guest Book and for all his views. I can't even describe to him how much he lights up when he see's that he's had over 150 hits to his web site in 1 single day. He feels your love. As for the web site, we are attempting to change things around and make a "respond" column to the blogs. Bear with us. We may end up switching servers to make sure our goal is met. The goal: to make Gregory's web site exactly what he wants it to be! I can not thank Kathy Linder in Minnesota enough for her endless efforts designing and keeping Gregory's site updated and beautiful. She is a true blessing to our family brought by Aunt Nicole. We thank all who have said our web site is beautiful but we will not take any credit....the web site is Kathy's doing and it is why it is so beautiful!

Please remember to trust in God with all your hearts.

Peace,  
Ann