

Mom's Blog Entry July 18, 2007

We've been asked many times to set up a "journal" or "daily blog" to keep everyone informed. Please check back often as we will continue to write updates.

First and foremost, thank you to everyone for your continuing prayers, loving support and concern. Many of you we do not know personally and to us it is truly a blessing that Gregory has been touched by so many wonderful loving people. To those who know us well, thank you for standing beside us throughout the past 15 years, riding this roller coaster, holding our hands. Originally when we accepted the invitation from the Naples Daily News to tell Gregory's journey publicly we were very aware that the time may come when we could possibly be facing the finality of this disease and the reality that his life may be taken from us here on earth. As painful as it is to go through this process we all feel very strongly about keeping everyone as informed as possible because we truly are grateful for everyone's support. We promise to not leave everyone wondering and hanging. You have all become part of our lives, our family, and we are so thankful every day for each and every one of you. We deeply feel your love, compassion and concern. Please know that everyone of you is part of the cradle that continues to hold Gregory gently and you all play a tremendous role in him maintaining his fighting spirit. Gregory is very much alive with hope and feels your love. His desire to fight to live is stronger than ever.

Yesterday I reminded Gregory that he had once said he wanted to "make his mark" on earth, something I was ever so proud of him expressing. I truly believe that Gregory has not made a mark but a massive indentation because his strength and perseverance has been truly inspirational to so many. I can not speak for anyone else but I can truly say, without hesitation, that there is no tiny ink dot made on my soul, that's for sure. Gregory has truly engraved himself for generations and I am thankful to him for sharing his story with the world to help other's through their struggles now and in the future. As I have said to him so many times, "Gregory, you 'get it', the true meaning of life".

I'm not sure how in the world I can explain the range of emotions that go through us in one 24 hour period of time. One minute we're crying with tears of sadness and then within the next several minutes we're laughing about something stupid. Yesterday we met with the Naples Daily News reporter, Jennifer Brannock, the woman who has eloquently told Gregory's story to the public through her newspaper articles. When I was asked about my feelings at this particular point in time I had no trouble telling her my message, "all evil needs to be overshadowed by good in order to squelch the evil from winning. I will not allow the evil to break the spirit of this family. This disease is evil and it may take my sons life but it will never take away his spirit." That is a belief I have held deep within my heart for the past 15 years. It has helped me with my own personal growth and I have hoped that I could teach it to my children to help them face life's challenges with strength.

My son, shy as he is, more than likely could never have foreseen the tremendous compassionate response he has received on his journey and to be quite honest he is in amazement that so many are inspired. This was quite evident to me watching him walk back to his chair at graduation when the entire stadium erupted with a standing ovation, beginning with his graduating peers. He has told me it was as if he were floating on a cloud and he will never forget the outpouring of love he felt at that moment. To tell you a little piece of Gregory that some might not know, he has this part of his

personality yearning to help others. When Gregory see's someone in need of help or in pain he is always so deeply affected and immediately wants to reach out. Having this tremendous support from everyone has done exactly for Gregory what he has always wanted to do for other's. AND MOST IMPORTANTLY, it has fueled him to continue to fight his disease. Through the past 5 months Gregory and I have had many deep mother/son talks about life, past, present and future. He has shared with me things that have opened my eyes to the fact he is no longer my baby but a grown man. (When that happened I'm not sure. Apparently time does slip through one's fingers quickly in a blink of an eye.) What is apparent to me now, as I reflect back on remembering his adolescent years in his early teens, is that Gregory has felt a very strong purpose that brings him a tremendous amount of joy: He wants to help other people in their lives.

At this time Gregory is doing fairly well physically. We did go through a rough week last week with his appetite and physical strength slowing but happily I can report that this week has been better with his pain control more manageable and his appetite increasing. Barbara, his nurse at Hospice of Naples and Dr. MacArthur have been wonderfully helpful managing Gregory's condition keeping him in a more comfortable state, giving to him a good quality of life. Because the nature of this disease and its unpredictable behavior it is impossible to say where things will be tomorrow so with that thought we choose to live each and every day as it comes, not looking forward, not looking backwards. We are just living in the present and being thankful for the day we are given. Gregory continues to keep us all uplifted with his strong sense of survival. He will be the first one to tell you that he does not believe it is his time yet, that there is much more he's here to do. No one in this house has given up hope.

Lastly, I say these words over and over every minute of every day:

Trust in the LORD with all your heart,
And lean not on your own understanding;
In all your ways acknowledge Him,
And He shall direct your paths.

Peace,
Ann