

Happy Spring moving onto Summer, April 14, 2011

I thought that I would take the time to send you an update as we move into our 10th year of living with Lafora disease. There are many moments when I take a moment to think about the impact of this disease on our life. Scott, Matt and I live with the consequences of this disease and I often wonder what our life would be like if we never had this disease become a part of our life. My thoughts are dependent on the mood of the day. Sometimes I grieve. It is painful to lose our freedom of doing the simple things in life...just taking off and running an errand without planning to have help to care for Matthew. I miss traveling, getting together with friends and working!! Then I switch my mood and try and think of all that I have to be grateful for. I have 80/84hrs. of private duty nursing filled, I have a roof over my head, some money in the bank, food on the table and Matt is still with us.

Often friends will call and share what is going on in their life. I listen and encourage their communications. Then I sit back and start to wonder. I catch myself dreaming of what could have been. Where would our Matthew be in this world? What school, what career path would he have chosen? What lifestyle would Scott and I be living? For now, we are limited to just the dreams of what could have been and the reality of what is.

In the meantime, life moves on. I heard this week that another old friend has passed away suddenly. Another has experienced a brain injury that has left him temporarily in a Nursing Home. They are both in their 50's. Neither they nor their family had anticipated this sudden change in their life. This song from the band Nickleback is a reminder of the gift of every day.

"If Today Was Your Last Day"

My best friend gave me the best advice
He said each day's a gift and not a given right
Leave no stone unturned, leave your fears behind
And try to take the path less traveled by
That first step you take is the longest stride

If today was your last day
And tomorrow was too late
Could you say goodbye to yesterday?
Would you live each moment like your last?
Leave old pictures in the past
Donate every dime you have?
If today was your last day

Against the grain should be a way of life
What's worth the prize is always worth the fight
Every second counts 'cause there's no second try
So live like you'll never live it twice
Don't take the free ride in your own life

If today was your last day
And tomorrow was too late
Could you say goodbye to yesterday?
Would you live each moment like your last?

Leave old pictures in the past
Donate every dime you have?
Would you call old friends you never see?
Reminisce old memories
Would you forgive your enemies?
Would you find that one you're dreamin' of?
Swear up and down to God above
That you finally fall in love
If today was your last day

If today was your last day
Would you make your mark by mending a broken heart?
You know it's never too late to shoot for the stars
Regardless of who you are
So do whatever it takes
'Cause you can't rewind a moment in this life
Let nothin' stand in your way
Cause the hands of time are never on your side

If today was your last day
And tomorrow was too late
Could you say goodbye to yesterday?

Would you live each moment like your last?
Leave old pictures in the past
Donate every dime you have?
Would you call old friends you never see?
Reminisce old memories
Would you forgive your enemies?
Would you find that one you're dreamin' of?
Swear up and down to God above
That you finally fall in love
If today was your last day

As for now, my precious son is suffering so. We once again had to bring him to the hospital. Matthew had a seizure every hour from 11:30pm to 7:00am, then a cluster of small seizures from 7 am to 8 am one Friday night to Saturday morning. This occurred despite increasing his seizure medication twice within the previous week. He was experiencing breathing problems every afternoon. Our physician from Children's encouraged us to try and deal with it at home. Scott and I felt that we were too exhausted, we needed help to try and figure out a way to make this disease more manageable. So we went to the hospital. After 5 days in the hospital we learned that Matt had a urinary tract infection. They gave him 2 days of IV antibiotics and sent him home with a prescription for an antibiotic I had never heard of..Suprax. He was on that drug for 3 days then he started with terrible diarrhea. Within 48 hrs we learned that he had C Difficile, a horrible bacterial infection. Scott and I were dealing with a nightmare. For 3 days and nights we cared for Matt. He had a fever and could not keep anything in him. He is now on the powerful antibiotic Vancomycin, which has helped. He is wiped out, and so are we.

Scott and I rally in the time of need. We find the emotional and physical strength to care for Matt no matter what. But when we have the chance to step away and feel and experience some normalcy of life, it hits like a ton of bricks. Life is happening all around us. We miss the laughter and joys of our friends and family. We miss the freedom and experiences that life has to offer. But most of all...we miss our Matt. He is still with us, but slowly and painfully fading away. His body suffers so and there is nothing we can do but grin and bear it and make the best of a bad situation.

So friends.... I hope that you recognize all the good of today, Today is gift and not a given right. Enjoy the gift for us and Matthew. I am sure that if Matthew had his way he would be enjoying life to the fullest.

Lisa