

# My Days of Counting Are Numbered

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My daughter, Sydney, was diagnosed with Smith-Magenis syndrome (SMS) on Wednesday September 5, 2007 at 11:30am. I am able to be that precise because it is a date and time that will forever be imprinted on my brain. I have been counting the days ever since as if the diagnosis will disappear if I simply wait long enough. In fact, I have been counting a lot of things ever since that date. Time itself has taken on new meaning for me and I am not sure that it has been a healthy or productive change.

For the past 3 years I have written a short blog on the “diagnosis anniversary”. It has been helpful and even therapeutic in many ways particularly to document or journal how far I have come and recognize and accept how far I still have to go. I am no longer confident it is therapeutic for me to continue to count the days and years that SMS has been a part of my life. I am starting to feel it may be more beneficial to focus on what Sydney has accomplished, what our family has overcome, what our foundation is doing to further her cause and finally, what I have learned in the process. It seems to me a much more productive approach to things.

Numerous milestones have occurred this past year that has me thinking about the concept of counting and the significance of numbers. The first was Sydney turning 5. It was a very emotional day for me as she is so far biologically

from her chronologic age that I just end up focusing on all things she can’t do rather than the things she can. At one point I found myself feeling defeated and spiraled into a “pity party” mentality (my husband tells me that all the guests have left and I should move on...) that took weeks to leave. All the while, missing the many developmental gains she had made since her 4th birthday.

The second number hurdle I overcame was Sydney’s IQ test. I wrote about this in a previous blog (June 16, 2011). In the end, I did allow myself to find out “the number” and it was not what I had hoped for but was exactly what I expected. But that number, I have come to realize, only validated the fact that Sydney would be eligible for support services for the rest of her life but did not change who she is or what she can become. I had to work hard not to allow this number to consume me and feel devoid of hope for her future. I wasted valuable hours and days to prevent that number from being the very thing that defines her. I know now that there will be some people that only see her as that number but that most of the people that truly care for her will not; it is with these people that I will forge ahead and together continue to improve her world and how she relates to it.

The third number was my 40th birthday. How and when did I get here? It made me take a long hard look at myself and what exactly I have been doing for the past 40 years. It also forced me to make some important decisions about how I want to live the next 40. Sydney has taught me that there are no guarantees of any kind in life. She has forced me to take life one day at a time and in some instances one moment at a time. Only now do I realize how important it is to make the moments in our life count. They should have meaning and be filled with goals and objectives. As I reflect back at my first 40 it was all about getting somewhere and not so much about

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the journey. For my next 40 I hope I can stay focused on what I will be doing instead of how fast I can do it. Age is simply a number and I will not allow it to define me.

I think when you get caught up in “counting” or a particular “number” you end up feeling rushed as if there is somewhere else to go or get to in order to change that number. Instead I now prefer to embrace my accomplishments as opposed to counting time. I realize nothing in my life can be rushed and although there are places I want to go and numbers I will always want to run from I cannot get there any faster by dwelling on them. Living with a child with special or intensive

needs is a slow process in terms of true acceptance, understanding their abilities, and measuring their progress. I no longer intend to move quickly. Pacing myself has become a big part of my life and counting just works against me.

I will never be able to forget the day SMS changed my life. I now (and it was no small feat) prefer to celebrate it as a day of enlightenment as opposed to a day of tragedy.

I will no longer be counting how many days or years have gone by but instead periodically recognize the growth and development of myself, my daughter, and my family.