My Daughter

By Eric Fier

I find it strangely difficult to write about my daughter, though this wasn't always the case. After Rachaeli was diagnosed, writing was my only outlet. I wrote for hours about my mixed emotions, trying to probe the depths of my soul as I wrestled, in prose, with the reality of my daughter's illness. It was a rich and cathartic form of self–help, one that allowed me to process all that was changing so quickly around me. In my lonely Tay–Sachs universe, with my writing I felt far less isolated. On paper, I artfully developed an entire schema devoted to appreciating why God chose us to care for Rachaeli's fragile body and perfect soul. I spent months developing Rachaeli's website (www.rachaeli.com), channeling all of my mixed passions into this venue. Simultaneously, as I embraced my daughter, I also embraced the intense array of emotions that accompanied my new reality. Tay–Sachs enveloped my life. Right or wrong, my dying child began to symbolize all of my dreams and fears and gifts. My emotions were raw and exposed. I cried with little precipitant; no subtlety of poignancy seemed to escape me. At my computer, my words flowed like my tears. And though I felt broken, I knew, together with my Rachaeli, I was very much whole.

Today, Rachaeli is almost 3 $^1/_2$ years old. I used to fight to keep from seeing the Tay–Sachs peek through the personage of my child. Now I fight to see glimmers of my child peek through the Tay–Sachs. While I embrace every stage of this process as a spiritual journey – my metaphysical connection with my daughter inversely strengthening as her physicality slips further out of my reach – I can't help but hurt when I look at photos of my "healthy" Rachaeli. I hardly recognize the smiling infant in the picture. Her eyes are alive and bright; her smile communicates such exuberance. I am reluctant to admit it, but I don't really remember those smiles. I know there was life before Tay–Sachs; it's just that I seem only to recall everything since. It sometimes feels like life began only after Rachaeli's diagnosis; probably a sad testament to how little I truly appreciated— until I recognized how briefly I would be allowed to keep it. My angel looks tired now. I miss the smiles I only faintly remember. Last week, I heard her giggle on a video; I couldn't believe my ears. I wanted to cry. But tears don't come so easily anymore. The wall around me is harder to penetrate. I can feel myself closing off. I write much less. I am girding myself for pain. I sometimes question who is exiting first.

Over the past 6 months, Rachaeli seems to have stabilized. Or so I tell myself. On *Zavesca*, a substrate inhibitor, we have seen few new seizures; we have endured few new aspiration pneumonias; we have experienced few new medical crises. Perhaps "stable" is a misnomer; Rachaeli is quietly present. As a family, we are now well acclimated to the ongoing challenges of "raising" a dying child. We have become a professional hospice team. I don't cry at all, anymore. I just wait. I hate feeling like I am waiting for the inevitable. So I tell myself I'm waiting for a miracle. And while I treasure each day, I am fearfully cognizant that making new memories will be difficult. Today, all of Rachaeli's photos look the same; she is flaccid, occupying whatever position in which we prop her; her eyes are soft and distant. There is a warm glow that enshrouds her. Only the background seems to change. Rachaeli remains my same perfect angel. Almost frozen in time.

So I return to build my spiritual connection with Rachaeli; it feels like the only vehicle through which we can now communicate. As all else seems to progressively weaken, our spiritual bond is the only system I feel I can fortify. I can no longer ascertain which of her 9 medicines provides true comfort; but I can see that she feels my prayers, as I whisper softly in her ear.

Each day, I ask God to ensure that:

- Rachaeli feels our love
- Rachaeli always knows how much she is treasured
- Rachaeli's heart rejoices in the knowledge that she is forever our perfect angel

Together, we are one soul.
Tay–Sachs cannot take that from us.

Several weeks ago, at the Tennessee Aquarium, I sat alone in the Butterfly Garden. I watched as thousands of jeweled–colored butterflies flapped their wings across the indoor rainforest that is their home. After some time, a delicate, perfect butterfly alights on my finger and, for several minutes, allows me to study its beauty. The rainforest guide stops and explains that the lifespan of a butterfly is little more than a few weeks. I smile warmly with the understanding that some of the most beautiful creatures grace the world with their perfect presence for just a brief window in time; just long enough to add a small dose of pure beauty before moving on. I return home and hug my baby tightly.