

## Zebras and Unicorns

Written by: Chaya Friedman

"There is nothing cute," she told me emphatically. There is nothing endearing about changing a diaper on a twelve-year-old. The bright eyed, clear skinned slim young woman can only be described as a queen. Her calm demeanor and smiling face gave no hint to the tumultuous existence that was her reality. We were standing together at the edge of a dance floor full of whirling twirling dancers. The occasion was a Melave Malka of sorts for families with children with atypical needs.

I do not remember the diagnosis of her son, as I'm sure she doesn't remember mine. Come to think of it she almost certainly doesn't remember the exchange. Do you know why? Because there was nothing unusual that happened that night for her. In retrospect it was a sentinel event for me. I finally found someone honest. Honest and real and accepting of her situation, while in no way loving it. I consider her a model.

Those of us who have extra special children who have a syndrome whose first name isn't Downs have a different journey than the Downs parents. Being lumped together with the Downs population is frustrating, as though while all of our children have special needs those needs are utterly dissimilar. Its like comparing apples and fabric softener because both are nominally groceries. Special education professionals, paraprofessionals and volunteers have pretty clear guidelines in caring for children with Downs. Of course, each child is unique, his or her own person with unique personalities and strengths and weaknesses. Nonetheless, there is a similarity. I have been told that in classes that are a mix of syndromes, the Downs kids stick together in an almost cliquy fashion.

One of the more fascinating data bases I've discovered in my nine years or so as a special needs mom, is NORD the national organization for rare disorders. The number of things that can misfire in a child is astounding. We should legitimately be shocked by the birth of a healthy child. But this is a nes that is cloaked in Teva. Within our community there are so many families that would look to the symptom list in an unusual syndrome and nod knowingly. Yes, this feels familiar, finally someone understands!

The old adage says "when hearing hoofbeats think horses not zebras" we, non-Downs moms certainly think zebras. And some of us are rarer than Zebras we are unicorns. There are many things that are the causes of the lonely struggle of the Zebra and Unicorn set.

First, there are so few with whom they share a diagnosis. If the diagnosis is one in five hundred thousand, its unlikely that there will be a family in their school district who struggles with the same. And even if you do by some miracles find another family with whom you share a diagnosis, many of these syndromes have a wide range of symptoms. For example: Mrs. D has children who struggle with syndrome E. per NORD this syndrome has a frequency of 1/200,000. Another family was located with the

same syndrome. In family F, it is a de novo mutation while in family D it is inherited. In family F the learning issues are prominent while in family D there is more of an autism like presentation. You get the idea; it did not make Mrs. D feel more understood.

I have no solutions, but sometimes, at least for me simply knowing that other people are also members of the zebra and unicorn brigade is helpful. Its helpful to meet people who are real and honest about the challenges and the struggles of extra special parenting. Thinking about the future is sometimes the hardest thing. You can battle each day, but planning for the future requires an infusion of energy that is utterly superhuman.

But the most challenging part by far is the emotional jail we feel surrounds us by the callous and the clueless. *He is sooo cute. She is heaven... you are soooo special. You are amazing. I would never be able to. Is it hereditary... is he vaccinated*

Each of these comments does not allow the mother who desperately needs support and encouragement to get any.

Here I am ladies: it is hard

It does not get easier

Nobody really understands

OHI designation is the school district version of 'I don't have a clue'

You are allowed to be miserable sometimes

Hashem knew who lived in your house when he sent you the nisayon, the challenge is for you and your family.

You are entitled to short cuts

Yes, a good haircut makes a difference.

Chocolate solves most moods on an urgent basis. If chocolate doesn't work then try Chinese food.

Most of all remember that Hashem is holding on to you let your muscles go slack and feel the reassuring sensation of Hashem's embrace.