

In Response to Zebras and Unicorns

Written by: Esther

Dear Chaya and Baylu,

This letter isn't a direct response to yours.

Although I can identify more with Chaya's struggle, no two people have exactly the same circumstances or process it the same way.

But I am struggling with Bylu's letter and the narrative my mind has written about the Lucky Down's moms all these years.

I was so excited when my daughter was finally diagnosed with a very rare syndrome.

I know!

That alone would categorize me as a unicorn!

But getting a diagnosis was almost a badge of honor.

I was finally a hero instead of a 'meshugana'!

My daughter had a real problem, and I wasn't imagining it!

But the feelings didn't last long.

The blank looks when I share her diagnosis, the refusal to interview my daughter because of her diagnosis, not being accepted into a Sunday program...

To me it seemed as though Down's created themselves a separate category. They are somehow elite.

I'll never forget how it hurt when I told a friend how lucky I am, and she responded that I can't be a "Lucky Mom" because my daughter doesn't have Downs.

Or when I struggled to get my daughter to try on a dress in an empty boutique, while the only other child there was being treated like a royal princess because her last name is Down's.

I've heard similar sentiments from other "Unicorn Moms".

Oh, it is such a good feeling to write that.

I'm a Unicorn Mom.

I'm a Unicorn Mom!

I have a place now!

It's a lonely life to be a Unicorn but it's definitely a colorful one.

My daughter may be so rare that some geneticists have never met anyone like her, but she's still an adorable little girl.

A little girl with cognitive and developmental delays.

A little girl who needs OT, PT, Speech, a cardiologist, endocrinologist, a nephrologist, assistive devices, behavioral support, learning support.... a special needs child.

The rest of the world lumps us all together.

The Horses, the Unicorns and the Zebras.

Physically handicapped and cognitively delayed.

We are all one by them, for better or for worse.

But those on the inside seem to divide us.

Downs... and the rest...

It's hard not having ANY support from others with the exact same diagnosis and challenges....but there's so much we do share.

Therapists and doctors.

Insurance challenges and denials.

Behavioral challenges and medical mysteries....

Hearing your challenges of being a "rare Down's" increases my belief that we are all floundering in this loneliness and are desperate to connect.

The need to belong seems to drive us to segregate ourselves and create groups in our minds, and, unfortunately, in reality.

Maybe we, the Unicorns, Zebras, and even the Lucky Horses, should make a conscious effort to seek out a common denominator so that we can give ourselves the gift of connection and belonging we all need for this special journey.