

Go Ahead and Stare By Melissa Hogan

Normally, none of us likes to be stared at. Do we look bad? Is there something on our face? Do we look strange? Staring makes us feel... *different*. And for some reason, we've learned that being different is bad.

But being different can be good. In fact, it can be celebrated. And, it can even be stared at without anyone feeling bad about it.

That was how I felt when I recently attended the *Hunter in Focus* exhibit at Grand Central Terminal in New York City. *Hunter in Focus* zoomed in on the amazing differences caused by the rare disease Hunter Syndrome. But what it also did was to *celebrate* the beauty that one can find in such a condition and make it not scary, but joyful.

And it asked people to stare. No, it begged people to stare.

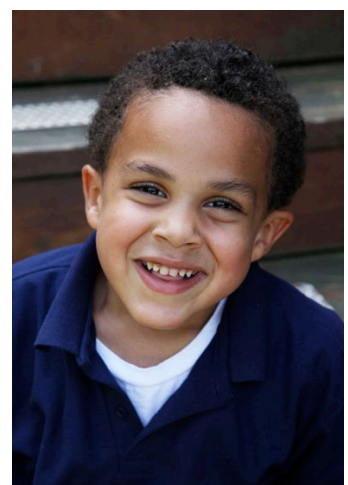
The exhibits were large, over six feet tall. And they featured a tracheostomy, enlarged features, curled fingers, hearing aids.... And they featured my son Case.

And because they were not live people and the photographs were so artfully done, it allowed passersby, both rushed and lingering, to take in someone who was very different from them. No one reminded them not to stare. They weren't made to feel awkward. They could look and linger and learn.

They could learn that difference was not bad. And that these *different* boys and men had families and hobbies, love and laughter. And that, in fact, they were *not* much different than they themselves, except for one unique chromosomal change.

It's that one chromosomal change in my son that has given us more heartache than we thought we could ever bear. But it's also given us more joy than we could have ever hoped for. And thanks to Rick Guidotti and Positive Exposure, we got to share that joy with thousands of people on a stage much larger than we'd ever expected.

Thank you





About the Author

The author's son Case was diagnosed with Hunter Syndrome in 2009 at the age of two. Case and his family were able to meet Rick Guidotti earlier this year at their home outside Nashville, Tennessee, for a photo shoot for the *Hunter in Focus* exhibit. Melissa writes a blog about Case's life and challenges and other issues related to rare disease at

www.savingcase.com.