

Dear Fellow Parents,

Twelve years ago, I sat in a chair and after days of genetic and metabolic testing on our one year old daughter, Olivia, at Children's Hospital in Denver, a doctor came through the door and confirmed the two words I didn't want to hear: Angelman syndrome. A few months before, my husband googled Olivia's symptoms, so I already knew the diagnosis was likely: small head, hand flapping, developmental delay, and trouble sleeping (which is the understatement of the century, am I right?) and with the Wikipedia result, our lives changed.

We've lived with Angelman syndrome a long time now, and I guess the first thing I'd want you to know is, it's not as scary as it initially seems.

Olivia walked at five. She's never had a seizure. She's got multiple sounds for words and for someone who cannot speak, girlfriend communicates clearly. Musicals are her favorite and I'll tell you what, if she wants to watch **Oklahoma!**, you're going to hear about it. She is sweet, funny, and very popular, and we just got back from a family trip to Mexico—something I wasn't sure was possible. Turns out, my angel loves laying in the sun and lunching on chicken quesadillas poolside. I like to tell people all the things Liv can do because I know it brings hope. But if I'm being perfectly honest, when she was first diagnosed, knowing all the things she might be able to do one day was not what I needed to know.

What I needed to know was that even if life looked different, it could still be beautiful. Is it hard? Sure. There are a lot of hard things about Angelman syndrome. But here is the thing no one tells you: when a child receives an Angelman diagnosis, the parent receives an invitation. An invitation that invites you out of self and into love. Any invitation that invites you out of self and into love feels terrible at first because a call to love is hard. But the more I step out of my self and into intentional love—beauty abounds. The more I look at her and think “what could I do to make Olivia feel loved and known and safe today” even to the detriment of my own desires—the more beautiful my own life gets. Love is like that. Love is capable of producing beauty in hard things.

Angelman syndrome can be hard, but your life can still be beautiful. Our children are gifts. I guess that's what I'd want you to take away. And who they're inviting us to become is a gift too.

And, while I'd love nothing more than to sit and encourage you a little longer, I have to go now. Love is calling, and she wants to watch Hamilton.

Krysta MacGray