



August 27, 2015

SmileZone Foundation
557 Chartwell Road
Oakville, Ontario
L6J 4A8

Dear Mr. Bachley and Mr. Graves:

On behalf of Grandview Children's Centre I am writing to you and your entire Board and team to express our sincere gratitude for working with us to create amazing spaces for kids and their families.

We know that the team at SmileZone have a deep understanding of the journey so many of our families are on. In the years of experience I have had in this field I have yet to be able to articulate as well as families the difference that support like yours means to them. With permission, I am sharing such a story with you from one of our families who is thrilled about the SmileZone at the Abilities Centre and excited to hear about what will be happening in Oshawa.

"What she didn't tell us"

To help you understand what your support means to families like mine, I'd like to take you back to November 4, 2010, in a completely unremarkable yellow room at our local community hospital; I remember every detail of that day, because it was the day our lives changed forever.

Our daughter was at school. Our youngest was 15 months old, and happy as could be in his stroller; he was oblivious to mommy and daddy's rising stress levels. My husband and I had both taken time off work to attend this appointment.

We had attended lots of appointments for our son over the months leading up to that day in November, but this one seemed more important, more formal. The phone message had said, "results are in and we need to see you as soon as possible." So here we sat, behind an oversized table, across from the geneticist. In hindsight, I think the table served as a buffer, a physical barrier between us and the news the doctor was about to deliver.

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Registered Charitable Organization

Inspiring possibilities for children and youth with special needs.

We learned that our son was missing a small part of one of his 9th chromosomes. A piece so small the first 2 sets of tests had missed it. You should never underestimate the size of something! That small missing piece of DNA included a gene, EMHT1. This gene is instrumental in a number of processes including speech production, muscle tone, heart and kidney formation, and brain development. Lacking this gene meant our son had Kleefstra syndrome: a very rare genetic disorder. He was the 124th diagnosed case of Kleefstra syndrome in the world. As doctors often do, the geneticist gave us the worst-case scenario: she said our son may never walk, would likely never speak, would have a severe developmental delay, and would never have children of his own. That small missing piece of DNA would change all our lives. Over the course of that short appointment, the geneticist said a lot, but it was what she didn't say that changed us the most.

She didn't tell us about the therapies that he would receive from Grandview Children's Centre would help him reach the goals we had been told may never be possible.

For example...

She didn't tell us about the physiotherapist who would motivate him to do just 2 more crunches at the end of each exhausting therapy session in an effort to strengthen his core and get him up on his feet.

She didn't tell us that his therapy team would shed tears along with us when, at 3 and a half years old, he took his first steps during therapy.

She didn't tell us about the speech pathologist who refused to accept that he would never speak, the same speech pathologist received an emotional voicemail message from me the night he said "Love You" for the first time.

She didn't tell us about the occupational therapists who would teach him how to eat with a spoon when we thought he would rely on a g-tube in his stomach for the rest of his life.

She didn't tell us about the social work team who would spend hours helping us fill out endless reams of paperwork for respite, equipment and home modifications.

She didn't tell us that Grandview Children's Centre wasn't just a building on a hill, but a place where a team of paediatric experts inspire possibilities for kids like him, and where the kids themselves inspire possibilities too.

On that day back in 2010, there were a few other things that geneticist didn't mention,

How could she know that his sister would be her brother's best friend and his biggest advocate? She had previously been too shy to speak to anyone

outside her immediate family; then, at Halloween, she boldly requested two treats at every house with steps, because trick or treating isn't very accessible in a wheelchair and she didn't want her little brother to be left out.

The geneticist didn't know about the families we would meet along our journey who would cheer his victories as loudly as we did. They understand what daily life is like when you are raising a child with special needs. They know that celebrating the small stuff is important because every great journey starts with a single step.

She didn't know that these special parents would become our closest friends and biggest support system: our Grandview family.

And there's one more thing:

The geneticist who explained our son's diagnosis to us didn't mention that his journey would make us a turn us into stronger family and advocates.

She never said his smile could make the worst day better, or that he would be our determined little hero and our daily inspiration.

The important information she shared with us that that day rocked our world, but as it turns out, it was everything she didn't say that changed our lives forever.

Thank you for supporting Grandview Kids

Scott and Adam, you and the SmileZone team are now a member of our Grandview family and can share in the pride of assisting families with special needs meet their goals and dreams. We believe deeply in your vision and we are inspired by your work and dedication. Thank you to the Smile Zone foundation for all you have done.

Warm Regards



Lorraine Sunstrum-Mann ECEDH, RN, BA, MBA
Executive Director
Children's Centre