



Abby's parallel paths help lead the way to 'one door'

Five-year-old Abby Dalgleish, described by her mom Christine as “the happiest, most cheerful little bug you will ever meet,” has almost completed junior kindergarten at the Ottawa Children’s Treatment Centre (OCTC). She loves school, knows her numbers and months, and is surprising her family with new knowledge and skills every day.

Christine credits her progress to both OCTC and the Children’s Hospital of Eastern Ontario – two organizations she is very “passionate” about.

“Abby’s OCTC story is inextricably linked to CHEO,” says Christine, “and not merely because they share the same campus on Smyth Road. It’s because we have always used both services in conjunction with the other.”

Christine is hopeful that the amalgamation of CHEO and OCTC – the two largest providers of specialized pediatric healthcare providers in the region – will create an even tighter link between the two.

Parallel Paths to Diagnosis

At the age of one, Abby was nowhere close to where her older sister, Olivia, had been at that age. She couldn’t stand on her own and was only making sounds, not saying words. The family doctor thought Abby was perhaps a bit behind, but just fine.

After a year and a half of little progress and at the ongoing persistence of Christine, Abby was referred to Neurology at CHEO and to CHEO’s First Words program. A resulting MRI, at the age of three years old,

revealed that Abby's cerebellum – the part of the brain that helps control balance and coordination – was not formed properly.

"This helped explain all of Abby's symptoms," says Christine. "Like her having lots of sounds but not being able to form them into words and being able to take a couple of steps, but not to walk. But it didn't give us a diagnosis, the WHY behind it, so we kept searching."

Abby was referred to Metabolic Genetics at CHEO with a working diagnosis of cerebellar ataxia. Her genes were also placed into the nationwide Care for Rare program being led by CHEO, which focuses on improving the diagnosis and treatment of rare diseases. Geneticists have honed in on a single gene that could possibly explain Abby's symptoms and lead to a true diagnosis.

"Having a diagnosis helps you connect with other people in the same situation. It also has the potential to help others in the future with similar symptoms."

About the same time, Abby was referred by CHEO to OCTC and things started to move quickly. Abby was assessed by occupational therapists, physiotherapists, and speech therapists and was referred to other appropriate specialists as well. "At this point, pieces started to really fall into place."

One of those pieces was preschool, and then junior Kindergarten, both at the Smyth road facility of OCTC. Abby, herself, is enamored with the OCTC school and looks forward to it every day.

"It is such a happy welcoming place. My heart is so full and happy when I walk in there, and I see these kids, and they're happy, and they're learning. And as a parent, you feel like you are part of the whole team."

Within the first few weeks of school, Abby's parents were invited to meet with the team. "The principal, teacher, therapists, therapy assistants. There were around 10 professionals all together, spending time talking with us about Abby. It was incredible."

Another example of this "teaming" that sticks out for Christine is how the teachers will bring specialists – like Abby's occupational therapist – into the classroom when the teacher or educational assistant sees that Abby is struggling with something. The teacher and therapist together look at ways to help Abby or to create adapted activities.

It is these types of connections with teachers and health professionals – in a continuum of care – that Christine hopes will become even tighter with the amalgamation of OCTC and CHEO, especially for those children with greater needs than Abby.

"The thing about Abby is that she is not sick. She has disabilities, yes, but she is a very healthy, robust, amazing, sweet little girl. She's not in crisis. So many families are. And so many who use the services of OCTC also extensively use the services of CHEO and have many admissions to the hospital."

"To have an even closer connection between CHEO and OCTC could be really valuable for kids and families. With the stronger, single system of care that this amalgamation promises, families will continue to get the benefits of both organizations, but within a single system. And that has the potential to be very powerful."