

Finishing Cédric's wish on a high note with a visit from Mickey and Minnie Mouse at Give Kids The World Village.



When you Make-A-Wish upon a SHINEing Star

By Mara Gervais, mom to SHINEing Star Cédric and Co President of the DLG4 SHINE Foundation

Exploring the powerful impact of charitable wish granting for rare disease families.

Wish granting agencies have existed for decades. Wonderful people created these non-profit organizations to offer gifts, often referred to as “wishes”, to children going through medical hardships and their families. The goal was to soothe the pain and lighten the burden of devastating health challenges, to allow children and families to experience joy and feel special, and possibly forget their difficult reality for a moment.

These days, most of us are familiar at least with the largest one of these agencies, the Make-A-Wish Foundation. But few know the scope of their work or truly grasp the power of these gifts. Many might think that the concept is limited and only applies to children diagnosed with cancer or life-threatening illnesses. And while it might have been true in the past, and might still be for certain agencies, many now have much wider criteria and grant wishes to any child and family whose daily life is made harder by a medical diagnosis. Each agency has their own criteria, some are limited to certain types of diagnoses, many are regional

and limited to a geographical area. But these days, thanks to the increasing awareness of what it is to live with any disability or illness and to the generosity of so many, it is likely any child living with a medical condition could find a wish granting agency for which they qualify.

The various wishes a child can make are also widely unknown and underestimated. People might assume wishes are limited to trips to Disney World. And while it is true that many children and their families chose this vacation, the world is their oyster. Not only can the wish be a vacation anywhere, it is by no means limited to trips. A child could wish for a hot tub, a bedroom make-over, or a backyard playground. Or they could wish to meet a sports team, their favourite singer, or to be on TV. They can even wish for a puppy. Of course there are limitations to what can be wished for and differences between various agencies. It is important to remember these are non-profit organizations and depending on donations. But the breadth of possibilities is truly amazing.



Visiting Magic Kingdom and providing this Disney-loving sensory-seeker with moments of pure joy and contentment.

Due to the various misconceptions or simple lack of knowledge, however, many families with a child with a genetic rare disease do not apply for a wish. As I write, I am only aware of 2 children with DLG4 SHINE who have been granted a wish. It could also be that hesitation and guilt play a role there. The fear the gift might not go well, might be wasted, or that we as parents and caregivers are not deserving of one because our children are not sick enough to warrant it, because their life is not threatened. But we are deserving! Our lives are impacted daily, in a myriad of small and big ways, by this diagnosis. Our mental health is affected. And more than anything, our children are deserving! They deserve the world, as any child does. And because they were born with this genetic disorder, it is harder for us as parents to offer it to them, the way any parent who brings a child into the world wants to do. And therefore we owe to them and to ourselves to accept the generosity of the philanthropic heroes behind these agencies and recognize that we are worthy of their gifts.

I myself had never thought of requesting a wish for my son, Cedric. And when it was suggested to me, my initial thought was that we could afford gifts and trips and should not take away a gift from another deserving child. But thanks to the encouragements

of a fellow mom, we applied and were granted a wish for Cedric just in time to benefit from it before he turned 18 and aged out. And this was so much more than the trip to Disney World we could have planned for ourselves. Everything was thought of and everything was taken care of. We didn't have to do any planning. We were made to feel special and cared for every step of the way, and the carefree happiness and contentment we felt during the trip acted as a balm for the soul and will linger and resonate for years to come. To say we are grateful is an understatement and we will never forget it.

And so I pay it forward and my wish for every DLG4 SHINE family is that this article will inspire them to search for an agency and apply for a wish. Allow yourself to dream of what could make your child happier, either for a little while (e.g. a vacation or meet-and-greet) or daily (e.g. a tricycle or a gaming system). You'll be amazed by the healing power of receiving a wish. To make it easier for you, we have started to compile a list of wish granting agencies DLG4 SHINEing Stars can qualify for and we will update it as we learn of others. You can find it on our website at <http://dlgshine.org/support-programs>.



Giving Cédric his Make-A-Wish Canada Wish Box filled with thoughtful gifts, t-shirts, and the announcement and countdown for his Wish Trip to Disney World.