

# MEET ADALIA

*For STEPtember 2023, we asked our coaches from last year if they want to continue on the same adventure with us again. They all answered yes. We asked them a few questions to hear how they have been over the past year. Thank you to Laurène, Adalia's mother, for taking the time to respond.*

## How was Adalia's year?

Adalia's year was difficult because she was diagnosed with absence seizures [in addition to the leukomalacia\* diagnosis she received when she was 2 years old]. We are trying a third treatment, hoping it will stabilize the epilepsy. Previous treatments have had heavy side effects. Adalia is unaware of her absences, and so it has been hard for her to accept the effects of the medication, which oscillate between drowsiness, loss of appetite, irritability, and depression.

## How has STEPtember impacted Adalia and your family?

Adalia was so proud to see herself on the publicity posters! It has played a big part in her self-esteem. For our family, it has also been very positive because it's allowed people around us to talk about Adalia's disability, when they hadn't dared to before. This helped us communicate better about it, wanting to reach new people.

## Were Adalia's objectives for this year achieved? If not, how did you bounce back?

Adalia's goals were, unfortunately, disrupted by the epilepsy. With all the side effects, our cutie was not always in the mood to concentrate, and she was severely fatigued. We decided to focus on her happiness and push back our deadlines.

And it worked well because today Adalia has surpassed our expectations. She knows how to remove her trousers, socks, cardigans, and can almost take off her t-shirt. When dressing, she knows how to put on her t-shirt, her cardigan with a little help, and her trousers basically by herself when she is feeling well.

She can write her first name and several letters of the alphabet. Her dexterity has also greatly improved in eating. Except for cutting meat, she is basically autonomous.

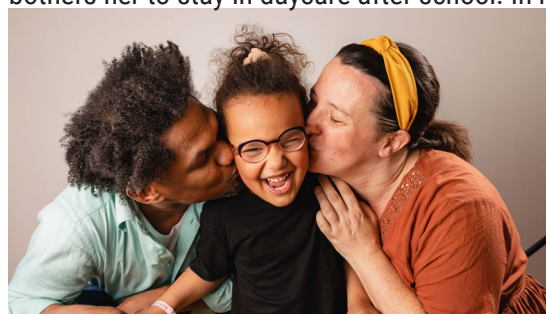
As for walking, after her last change in anti-seizure medication, Adalia surprised us by asking to walk holding hands... only one hand! It's still touch and go, but Adalia is getting there. Her balance is so much better, we are blown away! Except when she gets into a giggle fit... which happens often!

## How has cerebral palsy affected you over the past year?

Despite her disability and her difficulties stemming from the epilepsy treatments, Adalia had a good last year of kindergarten. She amazed us by performing a circus act in the school show, being invited to many of her classmates' birthday parties, taking part in a school trip to the farm, and she especially loved swimming lessons, where her disability became invisible.

Adalia is growing up. She will be 6 on September 16. She understands more and more that her disability is not very common, and she is constantly scanning for representation around her. I feel she needs to find her identity in order to develop. This is why an event like STEPtember is so important in our country. I hope other children with cerebral palsy will see Adalia on a poster and feel less alone.

From time to time, Adalia tells me she doesn't like having a disability, but in the same tone a child would say that it bothers her to stay in daycare after school. In no way does her disability take away from her joie de vivre!



*\*Periventricular leukomalacia (PVL) is a type of brain injury most common in very premature babies.*

*PVL is injury to the white matter around the fluid-filled ventricles of the brain. White matter transmits information between nerve cells, the spinal cord, and from one part of the brain to the other. PVL can cause damage to the nerve pathways that control motor movements, resulting in muscles that are tight, spastic, or resistant to movement, in addition to being weak. Babies with PVL have a higher risk of cerebral palsy and may have learning difficulties and other developmental problems. ©Boston Children's Hospital*



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Thank you Meagan Mason for the translation.