

INSIGHTS



Family reflections: Payton's asthma journey

Sheila DeVries¹✉

© The Author(s), under exclusive licence to the International Pediatric Research Foundation, Inc 2022

Pediatric Research (2022) 92:1481–1482; <https://doi.org/10.1038/s41390-022-02276-5>

I, Sheila DeVries, grant permission for *Pediatric Research* Journal to use the photos I have provided in their upcoming publication.

My name is Sheila. Six years ago, I gave birth to an amazing little girl named Payton.

Payton's wheezing and coughing episodes became more frequent. Our family made countless trips to the emergency department, which led to many stays in hospital.



When she was a toddler, Payton began having very bad eczema. We began to take her off different foods to see if it would help her condition. We switched to all-natural soaps and cleaning products, and organic food. Soon, she started to suffer from allergies and asthma attacks. We began having lots of doctor appointments, pediatrician appointments, and allergist appointments.



We tried numerous medications to determine which worked best for Payton. We ended up having to buy a nebulizer and oxygen reader so we could track her oxygen levels at home, to save us having to rush her to emergency each time they dropped.

Fast forward to 2021, her allergist requested blood work. The number count from her blood work indicated just how bad her asthma really was. He decided to put her on a shot called Nucala. Her allergist was able to get it covered through a company, so she

¹Milverton, ON, Canada. ✉email: info@pedres.org

Received: 9 August 2022 Accepted: 9 August 2022

Published online: 26 August 2022

began receiving this shot once a month. The shot made such a difference in her life. We had no more visits to the emergency department, and no more hospital stays. She was able to have a great year: Payton could run and play without constantly being wheezy and trying to catch her breath, like in previous years.

While receiving the Nucala shot, she was also on a pill-form of medication, nasal spray, three inhalers, three different nebulizer medications, daily allergy medications, and creams for her skin.

At the beginning of December, Payton was to go to her allergist appointment. But the day before her appointment, the office called and told us there was a delay in receiving her medication. Two weeks passed, and they still didn't receive the medication. They found out that the company that was covering the medication would no longer cover the cost of her allergy shot or medication.

We do not have coverage through my husband's work and most companies won't accept her to be covered since she already has a medical condition. As a stay-at-home mom to six children (and host to yearly exchange students), I do not have the benefits to cover all the expenses of Payton's medications, either.

Since the beginning of January, Payton has been put back on prednisone and has had to have numerous nebulizer treatments throughout the week so she is able to play without struggling to catch her breath. She hasn't attended school for the last 2 years, to avoid the risk of getting COVID. Her five siblings have not attended, either. They have all been doing remote learning since the beginning of the pandemic to protect Payton's health.

Our family is looking for a miracle to be able to get her back on Nucala. Her condition has definitely affected each one of us. We do all we can to protect her and keep her healthy so she does not have to suffer more than she already does. One of the biggest issues Payton faces is not being able to live her life like a normal child who runs around, goes to school, and plays sports. Payton

has had to give up dance, due to her breathing. This affects her socially, too: she's not been able to make friends through extracurricular activities and sports.

My husband and I have had to take many days off work and change our lifestyle to give Payton the best life we can while she is living with asthma. There is so much time lost from work because of hospital stays and emergency trips. I believe one of the biggest problems families face is the cost of medications and testing. For our family, special tests and blood work aren't covered.

I'd like to see researchers working on providing earlier testing for children at a young age. We would love to see more information and support for families with children with asthma. Families lack information about coverage for medications. It would help families if asthma was considered a disability, like so many illnesses are. The government could help cover days missed from work.

Our family would like to say a huge thank you to all researchers that work so hard to find cures to help children. Payton and our entire family would be so blessed and happy if a cure was found. To see our little girl running around and playing like a young child should, to see her attend school and make new friends and enjoy all the fun stuff in childhood... it would mean everything.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Sheila DeVries.

Reprints and permission information is available at <http://www.nature.com/reprints>