



Elkhart Student Leaps Two Grade Levels in Math with the Indiana Education Scholarship Account (INESA)

Once given six weeks to live, Ella is now a teenager and thriving. With INESA, she's able to continue her education despite medical limitations.

INESA Student: Ella Hunt Location: Elkhart, IN

Ella's diagnosis of spinal muscular atrophy (SMA) means her muscles don't work. While she has normal cognitive and social development, traditional school wasn't a fit and homeschooling burdened the family physically, emotionally, and financially.



A Mother's Perspective on Empowering Education Through the ESA

“The ESA has become our education utopia. It's not just a good thing; it's necessary. It allows Ella to have the social connections she so desperately needs, respects the boundaries of her medical condition, and still gives her a very rich education.”

-Erica Hunt, mother of INESA student, Ella Hunt

Ella Hunt seemed to be a healthy baby, developing normally, until she stopped moving her legs at around eight weeks old. Then, having just started to gain some head control, she lost it rapidly. What followed was a slew of medical appointments and a battery of tests.

The Hunts were fortunate, unlike many families, to get a quick diagnosis – spinal muscular atrophy (SMA), a genetic disease that causes nerves and muscles to waste away.

Ella was given six weeks to live and sent home with hospice and a Do Not Resuscitate (DNR) form.

“Can you paint a more tragic picture?” asks Erica Hunt, Ella's mom. “For some reason, I didn't feel like we were

supposed to sign it. I don't know if it was just the emotions of seeing my four-month-old's name on a DNR form or the hospice logo, but I couldn't do it. We felt that God had a different purpose for her life.”

“This Isn't Working”

The difference between SMA and other neuromuscular conditions is that the mind is not affected. “These are very intelligent individuals with very broken bodies,” explains Erica.

When the time came, the Hunts enrolled Ella in public school, then later switched to private school. Between early wakeups to get ready, and often, late nights at home, it was exhausting.

Because of her medical condition, Ella was forced into distance learning during cold and flu season. “A common cold could mean a life flight and possibly even a funeral,” warns Erica.

Distance learning created its own issues, especially once the school decided to pull the paraprofessional out of the home. Working with the para virtually versus in-person just created another obstacle.

Ella depends on an eye-gaze device exclusively to communicate and do her homework. When Ella couldn't find the download for a worksheet her para had sent, the para sternly asked what she'd been doing for the last 10 minutes.

Erica held it together, but inside she was screaming, “This isn't working!”

Ella Gains a Voice

That evening, Ella asked her mom, “Can I just not go back to school?” Erica’s heart sank, realizing they hadn’t really considered Ella’s opinion.

“I just knew at that point we had to come up with something else,” says Erica. “The social part of school was so important to Ella. She has normal social development and is very extroverted, but she was willing to sacrifice that because the stress was so high.”

House Rules

The Hunts transitioned to homeschooling, which allowed them to customize education to Ella and her needs.

“SMA makes the rules in our house,” says Erica. “As long as we live by those rules, Ella thrives. If we try to push those boundaries, we run into trouble and we’re fighting for her life.”

Homeschooling allowed them to better work within those boundaries, and Ella flourished.

“I Just Wanted to be a Mom”

In college, Erica knew she didn’t want to be a nurse or a teacher. Now she was both, and the pressure was intense.

“I just wanted to be a mom to Ella,” says Erica, “but that was low on the totem pole, because I had to be her nurse first, and then I had to be her teacher.

Erica did a deep dive into homeschooling to learn all that she could. She even hired a teacher to help, but it was only for a few hours a week. She and her husband Dan knew what kind of education Ella needed, but they didn’t have the finances to make it happen.

Enter the ESA: A Paradigm Shift of Possibilities

The Hunts had been homeschooling for about 18 months, and in the middle of that, Ella had spinal surgery. She almost didn’t survive and was left with a spinal cord injury and paralysis. Ella also lost a lot of oxygen to her brain which resulted in learning loss – equal to roughly two years of math.

Fortunately, Erica’s friend and fellow SMA mom had heard about the Indiana Education Scholarship Account (INESA), which provides scholarship dollars to customize education for students with disabilities. For the first time in a long time, Erica felt like she could exhale.

With the ESA, the Hunts were able to hire a teacher and pay her a fair wage, which was very important to Erica. They were also able to bring occupational therapy back into the home.

“Ella can’t move a muscle, but she’s a kinesthetic learner,” says Erica. “With school and online learning, there was this part of her education we could never really touch.”

In her current educational environment, she has hatched chicks and butterflies, she’s been on field trips to see eagles’ nests and trees, she’s been to a science park, and she’s toured factories. She also takes part in a choir and weekly classes with SMA friends.

“It’s just been incredible,” gushes Erica. “When she had her baby chicks, we set up an iPad above her bed and another over the incubator. She stayed up all night watching them, texting her teacher each time a new one hatched. She named them all.”

Ella’s Big Plans

That little four-month-old baby, who was only given six weeks to live, is now a teenager.

Over the past year, Ella has recouped those two years of learning loss in math.

She continues to progress in language and has taken an interest in writing. She writes poetry, and the Hunts have partnered with an organization to turn some of Ella’s writings into music. Someday, she wants to write a children’s book.

Advocating for those with disabilities, she wrote her own story and shared it with her councilman. She also did a couple of speaking engagements, using her eye-gaze device to write questions, answers, and encouragement.

Ella wants to be a babysitter and plans to take a babysitting certification course this summer. Her other big ambitions include learning more about our legislative system, our country’s history, and taking some historical trips.

Ella will also learn how to budget, how to calculate her needs, and grocery shop online. With plans to go to college and live in a dorm, she will need those skills. For the Hunts, INESA helps make Ella’s dreams possible.

“The ESA has become our education utopia,” says Erica. “It’s not just a good thing; it’s necessary. It allows Ella to have the social connections she so desperately needs, respects the boundaries of her medical condition, and still gives her a very rich education.”

Erica’s Tips for INESA Parents:

- 1 Find other ESA families.**
Families currently involved in the program have personal experience and insights. Ask them lots of questions.
- 2 Dream big.**
What does a dream education look like for your unique child? Erica recommends getting it all out on paper and then navigating toward that.
- 3 Be 100% clear on the process.**
Educate yourself on the process and expectations before jumping in. That will help you avoid pitfalls that can add tremendous stress.