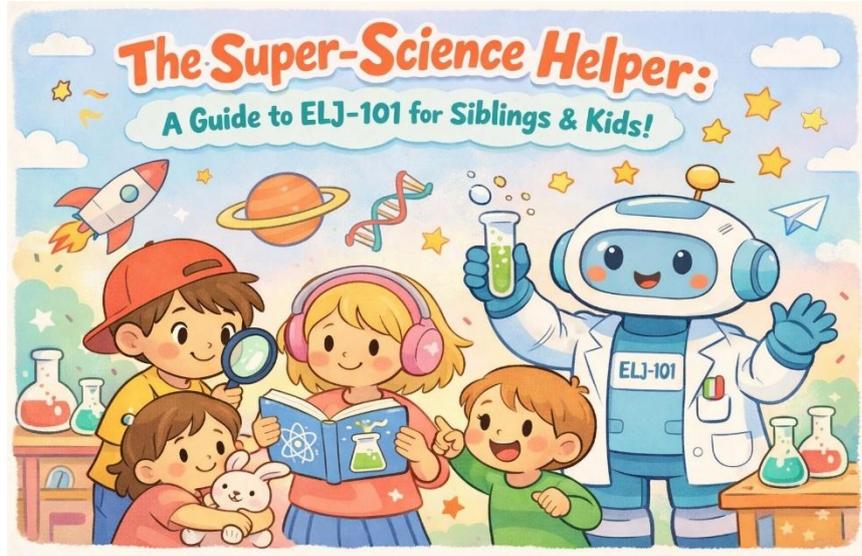


The Super-Science Helper: A Guide to ELJ-101 for Siblings & Kids!



Hey there!

If you're reading this, it's probably because you have a brother or sister who has something called CDKL5. We know that sometimes, having a sibling with CDKL5 means your house is a bit different from your friends' houses. There might be more doctors' visits, more equipment, and maybe things feel a bit "extra" sometimes.

We are Karen, Carol-Anne, Cristina, and Rodney. We spend our days thinking about how to make life better for children with CDKL5, and for siblings like you, too!

Today, we want to tell you some really exciting news about something called **ELJ-101**. It sounds like a secret agent name or a cool new gadget, doesn't it? Well, it's actually a "Super-Science Helper" that doctors are working on right now.

Because we know you're a big part of your family's team, we wanted to explain exactly what it is and how it works, using things you already know about.

The Giant Instruction Manual

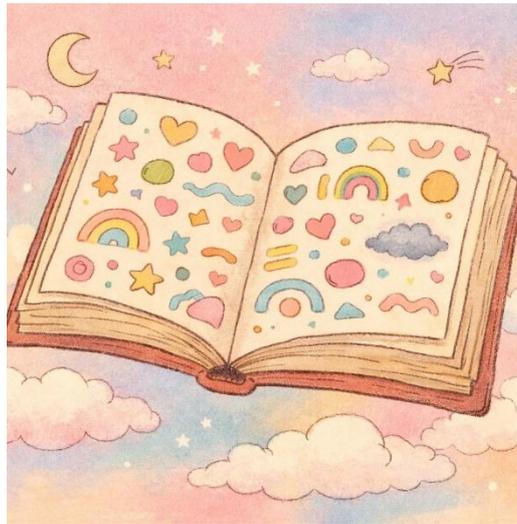
To understand ELJ-101, first we have to talk about how bodies are built.

Imagine your body is like the most complicated, coolest LEGO® set ever made. To build that set, you need a massive instruction manual. Every single person has one of these manuals inside them. Scientists call this manual **DNA**.

This manual tells your body everything: what colour your eyes are, how tall you'll grow, and how your brain should send messages to your arms and legs so you can run, jump, and talk.

In most people, the manual is perfect. But for your brother or sister with CDKL5, there's a tiny "glitch" in their manual. It's like one very important page was accidentally left out, or

maybe the ink smudged so the body can't read the instructions properly. Because that one page is missing, their brain finds it hard to send the right messages. This is why they might have seizures or find it tricky to move or speak.



Enter the Super-Helper: ELJ-101

For a long time, doctors could only help with the *results* of the glitch (like giving medicine for seizures). But now, scientists are trying something amazing. They are trying to fix the manual itself!

This is where **ELJ-101** comes in. ELJ-101 is what's known as "Gene Therapy."

Think of ELJ-101 as a **Special Delivery Truck**. Inside this truck is a brand-new, perfectly printed copy of that missing instruction page. The goal is to send this truck into the body, where it travels straight to the brain cells. Once it arrives, it delivers the new page so the brain finally has the instructions it needs to work better.

It's like if you were building a LEGO® spaceship and you realized a piece was missing. ELJ-101 is the person who flies in with that exact piece so you can finish the build!

Meet the Science Superheroes

This isn't just happening by magic. There is a whole team of real-life "science superheroes" working on this.

One of the leaders is a man named **Russ Addis, PhD**. He works at a place called the LouLou Foundation and is the head of the team at Elaaj Bio. He and his team of scientists spend all day doing careful research, looking closely at tiny details, and figuring out exactly how to make that "Delivery Truck" (ELJ-101) as safe and helpful as possible.

They are working really hard because they want to help your sibling feel better, just as much as you do. And it's not just them - there are lots of scientists, doctors, and families all around the world working on CDKL5 research too.

Why Is It Taking So Long? (The Video Game Rule)

You might be wondering, "If they have the delivery truck ready, why can't my sibling have it today?" That is a great question. The best way to explain it is to think about your favourite video game.

Before a big game like *MINECRAFT*® or *ROBLOX*® comes out with a huge new update, it goes into something called "Beta Testing." The developers don't just release it to everyone immediately because there might be "bugs" or "glitches" that could crash the game. They test it with a tiny group of people first to make sure everything works perfectly and safely.

ELJ-101 is currently in that "testing phase."

Scientists have to be **super, super careful**. They are starting with a very small group of people (only about 12!) to make sure the delivery truck goes to the right place and doesn't cause any other problems. They have to check everything a thousand times because your sibling's health is the most important thing in the world.

Even though it feels like it's taking a long time, it's only because the scientists want to be 100% sure it's safe before they give it to more children.



What Will the Super-Helper Do?

We don't know everything yet, but the hope is that ELJ-101 will help your sibling's brain "read" the instructions better.

This might mean:

- Having fewer or smaller seizures.
- Being able to learn new skills, like sitting up or using their hands more.
- Finding it easier to communicate with you.

It won't make CDKL5 disappear instantly: it's not a magic wand. Your sibling will likely still need their regular medicines and their physical therapy for a while. But ELJ-101 is like giving them a better set of tools to work with.

You Are a Hero, Too!

While the scientists are busy in their labs, we want you to know that **you** are doing one of the most important jobs of all.

By being a great brother or sister, you are helping your sibling every single day. When you play music for them, hold their hand, or just sit with them, you are helping their brain grow and feel happy. Science can do a lot, but it can't replace the love and fun that you bring to your family.

We know it can be hard sometimes when things feel slow or when you have to wait for "science" to catch up. If you ever feel frustrated or have more questions, it's always okay to talk to your parents or a grown-up you trust.



What Happens Next?

The "Beta Test" for ELJ-101 is hopefully starting in a year or two (around 2027). That might sound like a long way off, but in the world of science, it's actually moving quite fast! We'll be watching every step of the way and sharing updates when there's something new to know.

In the meantime, keep being the awesome sibling you are. You are part of a huge global team of families all over the world who are cheering for ELJ-101 to be the best "Super-Helper" it can be.

Thank you for being such an important part of the CDKL5 community. We think you're pretty "super" yourself!

With lots of hope,

Karen (USA - IFCR), Carol-Anne (UK - CDKL5 UK), Cristina (Spain - CDKL5 Alliance), and Rodney (USA - LouLou Foundation)

A Quick Summary for Super-Helpers:

1. **DNA** is like an instruction manual for the body.
2. **CDKL5** is a tiny glitch or missing page in that manual.
3. **ELJ-101** is a "Delivery Truck" that brings a new, correct page to the brain.
4. **Scientists** like Russ Addis are testing it right now to make sure it's super safe.
5. **Hope** is what we have for a future where the "Super-Helper" makes life easier for your brother or sister!

