Genomic Answers for Children's Health Act

It can take a long time for kids with rare diseases to be **diagnosed** or learn what disease they have. Genomic testing can help shorten this time.

But, Medicaid does not always pay for these tests even though they should. The **Genomic Answers for Children's Health Act** could change this.

Medicaid is a government program that helps people pay for health care. Each state has its own Medicaid program.

What are rare diseases?

Rare diseases are diseases that only a small number of people have. Most rare diseases are caused by changes in a person's **genes**.

- A **gene** is an instruction in your cells that tells them what to do. Like what color to make your eyes.
- Your **genome** is the word for all of your genes together.

Think of your body as made of blocks:

Each **gene** tells one block where to go.

Your **genome** is **all your genes together** that tell all the blocks where to go.

What is genomic testing?

Genomic testing is a medical test that looks for any changes in your genes. A change in a gene can be what causes a disease.

Doctors use **genomic tests** to diagnose (find) and know how to treat rare diseases. **Here's how:**

Doctors collect a sample from your body for the test, like your blood or spit.

A genomic test looks for any changes in any gene. This helps doctors diagnose a disease.

A diagnosis can help people get the right care or medicine they need.

How does genomic testing help kids with rare diseases?

It can take up to six years for doctors to diagnose a rare disease. During this time, kids may have to:

- Go to the doctor or hospital many times
- Miss school and time with friends
- Do lots of medical tests
- Get treatments that don't help

Genomic testing can be faster than tests that look at just one gene at a time. It can be cheaper, too.

A faster diagnosis means kids can get help sooner and avoid all these things!

Why aren't kids getting genomic testing?

Right now, not every state Medicaid program pays for genomic testing for kids. If Medicaid doesn't pay for genomic testing, it can cost too much money for a family to pay for it.

Let's hear from Rosa:

Hi, I'm Rosa!
A few years ago, I got really sick, but doctors didn't know what was wrong with me. They wanted to do genomic testing, but Medicaid wouldn't pay for it, so my family couldn't afford it.

I was at the doctor's all the time! I got many different medicines to try, but nothing helped me.

After two years and a lot of tests, my doctors finally found out I had a rare genetic disease. They gave me a different medicine that actually helps me. I don't have to go the doctor as much now and can spend more time at school and with my friends.

If Rosa had genomic testing, her doctors may have found her rare disease much sooner!

What will the Genomic Answers for Children's Health Act do?

This Act will help make sure every state Medicaid program will pay for genomic testing. It will also help hospitals pay for genomic testing when a kid is sick and must stay at the hospital.

The Genomic Answers for Children's Health Act would help kids like Rosa get genomic testing so they can get the right care and medicine sooner!

What should I say to my legislator?

1. Tell them your name and your story about living with a rare disease.

2. Tell them how this bill could help kids with a rare disease:
   - It can take people with a rare disease more than 6 years to get a diagnosis. This means lots of extra tests, time away from school, and added costs.
   - The Genomic Answers for Children's Health Act will help kids with rare diseases:
     - Get genomic testing paid for by Medicaid so more kids can get it if they need it
     - Get diagnosed sooner so they can get the right care and medicine sooner

3. Ask them, "What questions do you have for me?"

4. Say, "Thank you for your time!"

RDLA
Rare Disease Legislative Advocates
Youth & Teen Advocacy Day