



Noonan syndrome

WHAT IS NOONAN SYNDROME?

It's a **syndrome disease** that I've had for as long as I can remember.

In my body, there are many cells. In each cell, there's a recipe for making me. The doctor took some of my blood and found a difference in the recipe.

Noonan syndrome is one of a group of syndromes with similar conditions.

It affects both **boys and girls**.

Doctors find the syndrome:

- during pregnancy
- in babies
- in children
- in adults.

It disrupts **the functioning and development of my body**.

The conditions can vary from person to person.



IS THE SYNDROME VISIBLE?

The syndrome is often invisible.

There are also **conditions of Noonan syndrome that can't necessarily be seen**, such as :

- > heart disease
- > difficulty seeing
- > hearing difficulties
- > problems with the brain
- > kidney problems
- > problems with the testicles
- > sometimes tumors

And, conditions that can be seen also from the outside:

- > short in height
- > a typical Noonan syndrome face
 - low-set ears
 - drooping eyelids
 - wide forehead
 - wide-set eyes
- > teeth that are sometimes badly set
- > skeletal or skin problems.





DO I HAVE DIFFICULTIES?

Everyone has difficulties, but they're different for everyone.

I may have:

- > difficulty **eating as a child**
- > difficulty **holding my body and moving around**
- > difficulty **speaking**
- > delays and difficulty **learning**.



IS MY DAY-TO-DAY LIFE DIFFERENT?

Yes, because I may:

- > **get tired easily**
- > have **leg or joint pain**
- > need **help getting dressed or moving around**.



To help me, I may need:

- > **medical check-ups or appointments with doctors** to keep an eye on my health
- > **medical treatments** for
 - **growth**
 - **heart**
 - **attention and concentration**
- > **help at school, adapted equipment, day-to-day help for me and my parents**.



I might get service from:

- > **a speech therapist**. Who can help me communicate, speak and understand, write, read and count, as well as chew, swallow and eat.
- > **an occupational therapist**. Who can help me by adapting equipment and tools, or by guiding me to do what I want or need to do safely and independently at school, at home or at work.
- > **a psychomotrician**. Who helps me move better with my body and manage my emotions better.
- > **an orthoptist**. Who rehabilitates my eyes. He checks how well I can see. He can prescribe glasses.



I ALSO NEED TO KNOW THAT:

- > It's **not contagious**.
- > It can **change over time**.
- > I can't be cured, but **there are solutions that can help me have fewer problems**.
- > I can still **have friends**.



I can get help from:

- **my family**
- **friends**
- **doctors**
- **the Noonan association**.

