

# Noonan Syndrome

## What is Noonan Syndrome?

Noonan syndrome (NS) is a multi-system, genetic disorder affecting 1 in 1000-2500 people. Only one parent needs to pass on the gene in order for their child to have it. NS affects individuals with different severities.

### Physical Features

Many individuals with Noonan Syndrome have:

- Heart defect present at birth (~80%)
- Short adult height (5'5" men; 5'0" in women)
- Curved spine (scoliosis)
- Late start for puberty
- Sunken or protruding chest
- Feeding difficulties as an infant
- Hearing loss
- Poor eyesight
- Poor coordination- clumsy, not well balanced

### Facial Features

Facial features may be the most obvious signs and include:

- High forehead
- Very noticeable widow's peak
- Curly, thick hair
- Widely spaced eyes
- Bright green or blue eyes
- Large, low-set ears
- Short, upturned nose
- Prominent ridges between nose and top of lips (philtrum)
- Roof of mouth is higher than normal
- Small chin
- Short neck with extra skin (webbing)

An individual with Noonan Syndrome



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**For more information, visit:**

The National Institutes of Health: <http://ghr.nlm.nih.gov/condition/noonan-syndrome>

The Noonan Syndrome Foundation: <http://www.teamnoonan.org/>

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## What are the potential deficits?

### Speech and Language

Many people with NS have speech and language difficulties including:

- Speech sound problems, sometimes due to bad bite (malocclusion)
- Increased risk of speech problems when they have hearing loss
- Problems understanding what words they hear or read (receptive difficulties)
- Problems putting thoughts into words (expressive difficulties)
- Trouble understanding figurative language, like metaphors
- Increased risk for spelling and reading difficulties

### Social Skills

Many people with NS have trouble with social skills, such as:

- Trouble communicating with others appropriately (pragmatic language)
- Trouble noticing how others feel (alexithymia)
- Trouble expressing their own feelings
- Being overly nice when talking to others- “aiming to please”
- Feeling uncomfortable in social situations

## How we can help

Work in a team with special education teachers, occupational therapists, and speech-language pathologists to help children with NS be successful. Tips for the classroom include:

- Seat children close to the teacher and use visuals so they can hear and see what is going on (e.g. oversized books, large font books during story time)
- Seat children in areas of the classroom where there is less noise and activity to distract them (e.g. away from doors or windows, toy boxes; space small groups further apart during station rotations)
- Give short, step-by-step instructions with simple vocabulary *more than once* to help children understand and remember what you said. You can use gestures too! (e.g. “sit here,” instead of “put away your pencil before you sit down over there on the green square”)
- Give children extra time to respond when you’re talking to them so they can think and understand



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