

GROWTH IN NOONAN SYNDROME

Most children with Noonan syndrome will be shorter than average. However most will be at the lower end of the normal range rather than being outside the normal range. Part of the follow up for children with Noonan syndrome will be to have regular checks of their growth in the clinic. With the regular measurements it should be possible to make some predictions about their ultimately height.

If the paediatrician who has been monitoring the growth feels there is likely to be a problem he may refer the child to one of the paediatric specialists a paediatric endocrinologist who specialises in hormonal and growth problems. The paediatric endocrinologist will assess whether there it is appropriate to consider using growth hormone. To do this it will be necessary to undertake further hormone tests and possibly X rays of the wrist to see how the bones are developing. Growth hormone is given by regular injections and is expensive and therefore for several reasons a great deal of care is needed to decide if it is necessary.

Being short does not affect physical health and is not a "disease". However it may lead to a child being bullied or teased at school. For a sensitive child this can be a source of great unhappiness and is probably a reason for considering treatment.

The treatment with growth hormone will improve height by 2-4 cms but does not make a short child achieve an above average height. It needs to be taken for at least 2 years to obtain this increase. There is some debate about when treatment should start and for how long it should continue.

The other point to remember is that without treatment children with Noonan syndrome will enter puberty later than their peers. This may be a frustration for the child who feels left out of the more mature teenage activities but it also means that they have a greater potential for growth as they will continue growing for longer.

For further information, go to www.childgrowthfoundation.org/