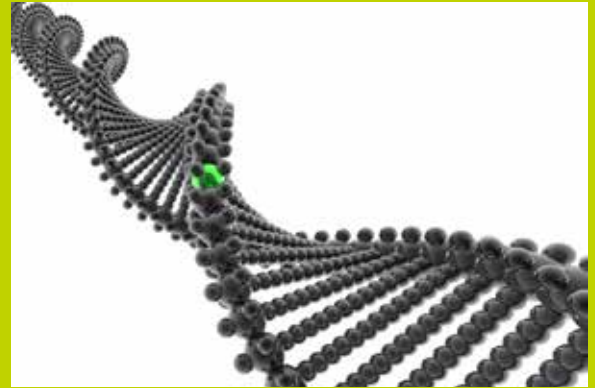


Tourettes Action guide to the Genetics of Tourette Syndrome



Since the 1980s it has been known that Tourette Syndrome can run in families. Probably most people with TS (but not all) do have other family members with some signs of the condition, including very mild tics or other features such as ADHD or OCD rather than tics.

Some genetic diseases are caused by an inherited abnormality called a mutation in a single gene. Examples include cystic fibrosis and Huntington's disease. Research in the 1990s showed that the genetic cause of TS is more complex as a single gene causing the condition has not been found, except in a very few families. For most people with TS there are variations in many genes that increase the risk of developing the condition compared to people without TS. It is possible to have some of these gene types without developing TS. We understand very little about the non-genetic factors that increase the likelihood of TS but this may include smoking and drinking alcohol in pregnancy. The risk of having TS probably develops in the womb and early life as other research suggests there is a difference in the way parts of the brain that control movement grow.

We are still learning about which genes and the kinds of variation in them that are important. This kind of research requires thousands of blood samples from patients and other volunteers who do not have TS to find more genes and to be more confident of the results. By 2017 a number of groups around the world are expected to have jointly collected 12 500 samples but more will be needed. We already know that there is an overlap between genes that are involved in TS and people with OCD or ADHD without tics. As these genes are identified they also teach us more about what causes the brain to function differently in TS.

As there is not a single gene for TS, there is not a genetic blood test that can confirm or diagnose TS in an individual, as there is for conditions like Huntington's disease.

Your family

If you have TS and you have children then there is about a 25-50% chance for each child that they could inherit sufficient TS genes and show signs like tics, TS, ADHD or OCD as they progress through childhood. The risk is independent for each child so for example a family with 4 children could find that all 4 are affected, or that none are, but on average 1 or 2 of the 4 may be affected.

During pregnancy or after birth there is no way of testing to see if TS genes are present. Our current knowledge and understanding suggests that there may never be a clinically useful blood test for TS because of the complexity of the cause, although it is hard to predict future advances. We are also unable to predict the severity of TS. Very often people with severe TS have close relatives with mild TS so if you have significant TS it doesn't necessarily mean your child would have a severe problem.

Deciding to have children can be more difficult when there is a genetic condition in the family. Our experience is that very few people with TS choose not to have children for this reason, but there are exceptions. If you need help to think about this it is probably best to discuss it with a clinician who is a TS specialist.

If you would like a copy of the Tourettes Action list of consultants who have indicated they have specialist experience in diagnosing and treating Tourette syndrome please get in touch:

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