



ALS/MND ETHICS

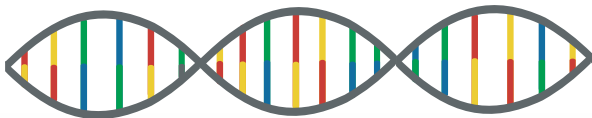
ETHICAL CONSIDERATIONS IN ALS/MND GENETICS

Genetic research, and genetically-targeted therapies, offer great promise for ALS/MND; however, there are also risks associated with undergoing genetic testing. Being aware of these risks ensures that individuals seeking genetic testing for ALS/MND are well informed prior to proceeding.

CONSIDERATIONS VARY DEPENDING ON THE INDIVIDUAL SITUATION

Symptomatic individuals, diagnosed with ALS/MND

- Genetic testing not only tells you information about yourself, but may also reveal information about your biological relatives, such as an increased risk for them.
- The social and emotional effects of genetic testing can affect family members in different ways and may cause strife between family members. You need to consider if, and when, to disclose results to family members.
- Genetic discrimination may be a risk to the individuals, or their family. Considerations include finances, insurance eligibility, eligibility for educational and recreational activities, family planning, and employment status.



Asymptomatic individuals, with a biological relative diagnosed with ALS/MND, and a genetic variant has been identified

- Individuals should consider if the knowledge benefits them, or if it burdens them. This is often a very personal decision.
- A positive genetic result doesn't tell you when you may develop ALS/MND, only the likelihood of developing the condition. As such, the timing of when to undergo genetic testing may present a challenge.
- There are psychosocial effects associated with both positive and negative results. For example, experiencing guilt can occur if an individual receives a negative test result.
- Individuals may be left with feelings of uncertainty and ambiguity.
- Genetic counselling and testing could help make decisions regarding family planning.
- Genetic discrimination may be a risk to the individuals, or their family. This includes finances, insurances, eligibility for educational and recreational activities, and employment status.

GENETIC DISCRIMINATION

Some countries have better protections than others with regards to genetic discrimination. Individuals seeking genetic testing should be informed on the protections, or lack thereof, in their local jurisdiction prior to proceeding.

Ultimately, the choice of whether or not to have genetic testing is a personal one. Individuals considering genetic testing should weigh the benefits against the risks specific to their circumstances, while evaluating the safeguards that can be put in place to protect themselves, and their family, against any potential discrimination.