

Could genetic testing make having a disabled child immoral?

The summer's "ice bucket challenge" has brought an extraordinary amount of attention to amyotrophic lateral sclerosis (ALS), a neurodegenerative disease impacting nerve cells in the brain and spinal cord.

What you may not know about ALS is that it is only very rarely inherited, at least through any determined genetic mechanism. It is currently [thought](#) that "only about 5 percent of all patients with ALS will have a genetic change" causing the disease. Genetic testing is available for patients who have both symptoms and a family history, but it is rarely recommended.

This does not mean that genetic testing for ALS will not be marketed to people concerned for their health, or for that of their children, especially given the peak in interest at this time. Genetic screening for the "breast cancer genes" BRCA1 and BRCA2 has become widespread, and prenatal genetic tests to detect them are also on the rise. But as with ALS, the vast majority of breast cancer cases have nothing to do with inherited genes.

Of course, there are plenty of traits that are more clearly and commonly linked to genetic variations. Prenatal genetic testing for such conditions significantly raises the stakes of what can be done with that knowledge.

All parents-to-be must be able to make their own choices about their ability to raise any child, but unfortunately too many are presented with a prenatal diagnosis without accompanying information about what it actually means for their child or their family.

The slick marketing of prenatal genetic testing has sparked concern about its propensity to dehumanize conditions while normalizing specific responses. This is certainly true for the most frequent chromosomal disorder, Down syndrome, which has also been a prevalent media subject this summer thanks to a couple of strange and sad happenings.

Read the full, original story: Disability will never be immoral