

Ethical and Legal Issues in Neurology: Chapter 22. Ethical issues in neurogenetic disorders (Handbook of Clinical Neurology)

Peter B. Kang



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The field of neurogenetics is moving so rapidly that new discoveries are announced almost weekly. The tools available for the diagnosis of neurogenetic disorders have become powerful and complex, and raise new ethical dilemmas that did not exist just a few years ago. In addition to previous concerns about presymptomatic genetic testing and carrier testing, the widening availability of next-generation sequencing raises concerns about the reporting of incidental findings of unclear significance. Genetically targeted therapies have now been proven to be efficacious for a few neurogenetic disorders. These therapies are generally quite expensive compared to other treatments. Given the cost constraints that will be needed in the healthcare system in the United States and other countries, and the likelihood that new genetically targeted therapies will be introduced, society will face difficult questions regarding its obligations to fund expensive therapies both for large populations and for small numbers of patients with rare diseases. Potential conflicts of interest involving both individuals and institutions will need ongoing vigilance. Scientific advances will continue to raise consequential ethical questions in the field of neurogenetics.

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