Opinion Article Open Access

Gene Editing Technologies and Ethical Considerations in Genetic Testing for Inherited Disorders

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Received: 24-Jun-2024, Manuscript No. JCEP-24-143843; Editor assigned: 27-Jun-2024, PreQc No. JCEP-24-143843 (PQ); Reviewed: 11-Jul-2024, QC No. JCEP-24-143843; Revised: 18-Jul-2024, Manuscript No. JCEP-24-143843 (R); Published: 25-Jul-2024, DOI: 10.4172/2161-0681.24.14.503

Citation: Frank L (2024) Gene Editing Technologies and Ethical Considerations in Genetic Testing for Inherited Disorders. J Clin Exp Pathol. 14:503.

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Description

The diagnosis, treatment, and comprehension of hereditary illnesses have all been transformed by genetic testing. With its deep understanding of genetic predispositions, it makes focused therapy, early diagnostics, and personalized medicine possible. But there are important ethical issues that need to be carefully considered as genetic testing technology improve quickly. A key component of moral medical practice is informed consent. Patients having genetic testing have to be adequately advised of the test's positive and negative aspects. This involves being aware of the genetic data that may be disclosed, the possibility of accidental findings (i.e., results unrelated to the main purpose for testing), and the consequences of any such findings. Prior to test, the counseling procedure makes sure that people are aware of the potential consequences, such as the possibility of finding mutations with suspicious clinical value. Patients need to be able to make independent decisions about their genetic testing. This requires the capacity to understand the information offered, decide in accordance with their values, and provide consent freely. It is a patient's right to decline genetic testing. Patients should be fully informed of the possible outcomes of their decisions, including the possibility that they may not know their genetic risks, before deciding to undertake testing. Genetic data is delicate and individualized by nature. To avoid misuse or unwanted access, genetic data confidentiality needs to be strictly maintained.

Strong security measures must be take in place by data security institutions to protect genetic data against attacks and illegal access. Patients should be made aware of the uses of their genetic data, such as research purposes, sharing with outside parties, and storage for later use. The ethical challenge of disclosing information about inherited illness risk comes when genetic testing discloses information that may affect family members. Genetic counselors and physicians must behave carefully in these cases, striking a balance between patient privacy and the possibility of helping family members who might be in danger. Genetic testing can identify an individual's tendency for specific illnesses, which could result in discrimination in the insurance and job markets. If an individual's genetic information suggests a high chance of having an expensive or incapacitating ailment, they might face difficulties in obtaining work or health insurance. The objective of laws like the Genetic Information Nondiscrimination Act (GINA) in the US is to protect people from discrimination in the job and health insurance markets based on genetic information. There are, however,

exceptions to these safeguards, and patients need to be informed about the legal system in their home nations. People who have specific genetic disorders or mutations may experience social stigma, which can negatively affect their mental well-being and interpersonal connections.

In order to address this issue, legislation that forbids stigma and prejudice must be supported as well as public education about genetic diseases. Given that many inherited illnesses follow particular patterns of inheritance, genetic testing frequently has implications for family members. This presents ethical issues on whether and how to tell family members who might also be at risk about the makeup of their genes. Genetic counseling can help families communicate with one another about possible risks and preventive measures as well as grasp the implications of genetic testing. In addition to having the right to know their genetic risks, family members can decide whether or not to get tested. In these circumstances, respecting individual autonomy is essential.

Early identification of hereditary illnesses through prenatal and infant genetic screening enables informed decision-making and early therapies. These screenings also create ethical problems. Based on screening results, parents have to determine whether to pursue more diagnostic tests or therapies. Making these choices can be difficult as well as mentally stressful, particularly when taking the child's possible outcomes into account. Ensuring ethical decisions involves making sure parents are fully informed about the potential consequences of screening results, including the risk of false positives or negatives. The selection of embryos based on genetic information presents ethical concerns when using this technology. Concerns regarding genetics and the possibility of social pressure to adhere to specific genetic standards are raised by the use of Preimplantation Genetic Diagnosis (PGD) for non-medical features (such as gender selection or cosmetic traits). To guarantee the responsible use of PGD and the rigorous evaluation of decisions' effects on the child and society, regulatory frameworks and ethical standards are required. Genetic mutations may be corrected by using emerging technology like gene editing (e.g., CRISPR). However, new technologies bring up important ethical questions about implications for future generations, possible side effects, and the longterm impact of genetic changes. Strong rules and regulations and constant ethical reflection will be necessary as genetic technologies develop to guarantee their responsible use and to assist individuals and families in making ethical choices about their genetic health.