IX. Managing New Genetic Knowledge

Findings from genetic research may present both foreseen and unforeseen challenges to racial and ethnic groups. As is discussed above, findings that link a racial or ethnic group to a disease or disorder can result in discrimination and stigmatization. However, new genetic knowledge can create more immediate challenges as well. The discovery of a gene affecting disease-susceptibility or drug-response can lead to significant uncertainty among both individuals with a gene-mutation and individuals unsure of their status. Often important information about the gene, such as the level of risk it poses or its distribution within the group, may not be immediately available or may be highly variable between studies. Furthermore, even once diagnostic tests become available for a gene there may remain only limited or controversial preventative measures available for individuals found to carry a mutated gene. Without clear information or clear preventative measures, new genetic knowledge can lead to confusion about whether individuals should get tested for or undertake certain preventive measures as well as to psychological conditions, such as anxiety, guilt, and depression. Because of the hereditary nature of most gene mutations these conditions often spread to family members.

Community organizations can play an important role in helping individuals manage new genetic knowledge. Once results from a genetic study are announced, community organizations can work to disseminate the findings among members of the community. This may take the form of public forums or distributing informational publications or advertisements. Especially as media accounts of genetic discoveries often exaggerate the conclusiveness of genetic findings, community organizations should take
care to present a comprehensive description of findings which clearly states what scientists know and what they are still unsure about. However organizations undertake educating the community, they should make an effort to continually update the community as new information about a gene or genetic condition becomes available. Often subsequent research on a gene not only expands knowledge about it, but also alters previous estimates regarding such information as the risk it conveys, its distribution within a specific group.

To help members of the community decipher and act upon genetic information some community organizations have also implemented or established relationships with genetic counseling programs. In such programs, trained genetic counselors provide individuals with information about a gene or genetic condition so that they can make informed decisions about genetic testing, potential preventative treatments, or reproduction. Most genetic counselors follow strict non-directive protocols, whereby they provide individuals with information about available diagnostic or therapeutic options but do not attempt to influence an individual’s decision. Community organizations may also choose to run support groups for individuals or family members affected with a gene or genetic disorder. Support groups can be effective in both educating individuals about a gene or genetic condition and alleviating associated psychological difficulties. Some organizations have established support groups specifically for carriers of disease-susceptibility genes in recognition of the different sets of challenges faced by these individuals from individuals with a genetic disease or condition.

Readings

Further Readings


X. Conclusion

As scientific research uncovers the genetic basis of human disease and health, it has become increasingly important to insure that all individuals benefit equally from genetic advancements. Towards this end there is a vital need for community organizations within racial and ethnic communities to work with genetic researchers to develop genetic studies that address both the methodological needs of researchers and the health needs of the community. It is hoped that this booklet provides a framework for potential collaborations between community organizations and researchers to achieve this
goal. The information provide here is meant to provide a general survey of the different ways in which community organizations can become involved with genetic research. Ultimately, in determining when and how to become involved in genetic research, organizations must evaluate their own capabilities and expertise, as well as the needs and concerns of both the community they serve and the researchers with whom they seek to collaborate.