

Access to Credible Genetics Resources Network (ATCG RN)

Establishing standards for accurate and credible information on single-gene disorders and providing tools for the development of quality materials.



ATCG RN is a collaborative effort toward the development of models to evaluate the quality of evidence on several aspects of genetic disorders – frequency and natural history of disease, diagnostic methods, and management – while taking into account factors that affect quality of data. Using information available in the public domain on Duchenne muscular dystrophy and fragile X syndrome, we are testing models to examine the extent to which we can determine the quality of information. We will develop strategies that will allow consumers of educational information to understand the origin and accuracy of information, as well as develop materials of their own.

Tools under development:

- Toolkit of Critical Elements for Quality Information
- Metric to Access the Quality of Information
- Quality Presentation Checklist

ATCG RN works to identify, develop, and deliver accurate information to affected individuals, their families and their health providers, promoting greater quality of health.

Genetic Alliance's partners on this project include:

- Parent Project Muscular Dystrophy
- FRAXA Research Foundation
- University of Maryland School of Medicine
- National Coalition of Health Professional Education in Genetics
- National Council of La Raza
- GeneTests/GeneClinics

For more information, visit: <http://www.geneticalliance.org/atcg>

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