

## **IDA Position Statement:**

### **APPLICATION OF GENETIC RESEARCH TO THE ISSUE OF EARLY IDENTIFICATION OF RISK FOR A READING-RELATED LEARNING DISORDER**

Although likely to be available in the future, reliable, inexpensive and widely available DNA tools for early identification of risk for reading disorders (RD) or dyslexia will take time to develop. Much more research is needed before we can use DNA analyses to significantly improve identification of risk for dyslexia beyond what we can already glean from family history and, later in childhood, from pre-reading assessments of reading related skills. While reliably informative genetic tests are currently impractical, genetic researchers are making progress. Below we provide information about the focus of genetic research and its potential uses in early identification, and then review the current status of genetic research before concluding by outlining considerations for assessing the usefulness of any potential ‘genetic test.’

#### **The focus of genetic research and its potential use in early identification**

Genetic research in the area of RD or dyslexia has had three central goals. To obtain:

1. A better understanding of the causes of RD.
2. A better understanding of how biology and the environment work together to effect brain development and function.
3. A better understanding of how these (brain development and function) effect learning to read for the better or worse.

As each of these goals are met, genetic research can eventually provide us with tools we can use to predict a person’s risk for RD. In theory, once the RD “risk” genes are identified, DNA tests could be applied early in infancy or even prior to birth to asses the likelihood that a person would develop a reading problem.

If a person with significant biological risk factor(s) is able to be identified, he or she might become eligible for special prevention and early intervention services, called an “at risk protocol,” administered by caregivers, physicians, schools and/or other professionals. This protocol might include:

1. Regular monitoring of language and learning development, looking for early and subtle signs of developmental learning problems
2. Advice, education and counseling for family members
3. Scientifically sound interventions and accommodations in or outside of the home, including reading-friendly modifications of the home, and specific preventative or remedial reading programs for the individual at risk.

#### **Current status of genetic research and future needs**

For now, what we do know is that the genetics causes resulting in RD interact in a complicated fashion and some of the results from studies need further clarification. The central blockades to developing useful DNA tests for RD are:

1. It is clear that not all of the RD risk genes have been found. While there are some consistencies, risk genes can vary person-to-person and family-to-family. It also appears that the development of reading disorders results from a complex interplay of both genetic and environmental factors. This essentially means that we have not found one or two major genes that can be scanned through clinical tests and cited as the “cause” for RD in everyone. The genetics of RD are very complicated and at this point in time, studies require a careful analysis of many possible genes, environmental and biological risk factors.
2. The results from many of the recent molecular genetic studies need to be replicated in other laboratories and on other independent samples of people.
3. The risk genes identified to date are also present in many children who do not have dyslexia. Thus, the risk genes appear not to ensure that any single person carrying them will have difficulty reading. People carrying the risk genes may express variable and inconsistent forms of reading-related difficulties.
4. Because of the ill understood genetics of RD noted above, a DNA analysis could also result in “false alarms” thereby identifying some people as at risk when these people would likely not develop a reading problem.
5. Conversely, some people develop a reading problem yet do not carry the risk factors that scientists have already identified. Thus, until we completely explain the biological and environmental causes of RD, we will be prone to missing some of the people that might otherwise be identified.
6. Even if genes are identified, the environment should not be discounted in terms of its power or contribution to risk or remediation. It is, in fact, environmental input that teaches the brain to read.

## Conclusions

In conclusion, it is known that dyslexia is highly heritable and that it can run in families. The evidence to date suggests a complex pattern of genetic influence on dyslexia that may involve several if not many different genes. For the time being, this makes informative and reliable genetic tests impossible. Yet it is probable that some time in the future we will understand the genes’ role in determining reading ability well enough to offer such tests. When this time arrives we will need to revisit this issue.

*The International Dyslexia Association (IDA) is a 501c-3 non-profit, scientific, educational organization dedicated to the study and treatment of the learning disability, dyslexia, as well as related language based learning difficulties. The IDA, founded in 1949, publishes results of outstanding educational, neuro-scientific, psychological, genetic, sociological and medical research on dyslexia, language, and literacy, and sponsors national and regional interdisciplinary conferences. It publishes and distributes books, periodicals and brochures of interest to parents and professionals.*