

Genetic Testing Guidelines

(Revised 1994)

Huntington's Disease Society of America, Inc.

Preface

The following guidelines have been produced by the Huntington's Disease Society of America to assist health care professionals in administering the genetic test for Huntington's Disease and to protect the well-being of those who choose to be tested.

The guidelines should be viewed as a framework of recommended procedures for testing; they are not regulations. Nevertheless, it is *strongly* recommended that pre- and post-test counseling be incorporated in any program of presymptomatic testing for HD along with the other preliminary screening sessions detailed herein.

This document represents a comprehensive revision of HDSA's *Guidelines for Predictive Testing of Huntington's Disease*, published in 1989. It incorporates many of the recommendations made at a May 1993 meeting attended by representatives of genetic testing centers and DNA analysis laboratories, and at-risk individuals. The meeting was jointly sponsored by HDSA and the Foundation for the Cure and Care of Huntington's Disease. The guidelines also embody the principle recommendations on genetic testing for HD jointly adopted in 1993 by the International Huntington Research Association and the World Federation of Neurology Research Group on Huntington's Chorea.

Most importantly, the guidelines incorporate the combined experience of many people on both sides of the test: the genetic counselors, psychologists, social workers, neurologists, geneticists, and others who have been charting this new territory since 1986, as well as those who have been through the testing process and emerged with various outcomes.

Finally, their combined experience has shown that no set of guidelines, however comprehensive, can account for every variation of the circumstances surrounding predictive testing for Huntington's Disease. Each center will have to decide how best to provide for each element of the testing protocol given its own particular staffing pattern, local population and accumulated experience.

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Huntington's Disease

Huntington's Disease (HD) is a hereditary, progressively degenerative brain disorder that affects the basal ganglia and the central nervous system.

HD is inherited as an autosomal dominant, so that each child of an affected parent, regardless of gender, has a 50% chance of inheritance. In addition, HD is 100% penetrant, meaning that anyone who inherits the HD mutation will develop Huntington's Disease if he or she lives long enough.

HD is a late onset disorder. Symptoms generally manifest themselves between the ages of 30 and 50. However, symptoms may appear at any age and a juvenile variant of the disease, usually characterized by rigidity, affects persons whose symptoms develop before adulthood.

Early Symptoms vary and are often subtle enough to go undetected. They may typically include minor twitching, clumsiness, changes in gait, lapses in judgment and memory, and in some individuals, behavioral changes, including depression and mood swings. The initial symptoms and progression of the disease vary widely. As the disease progresses, involuntary movements ("chorea") become more pronounced. Speech and swallowing difficulties often develop and cognitive ability deteriorates. In the later stages of the disease, the patient is usually bedridden and totally dependent on others for all of his or her needs. The patient eventually succumbs to complications such as heart failure or aspiration pneumonia.

Based on a prevalence of 1/10,000 it is estimated that HD currently affects between 25,000 and 30,000 Americans. A further 125,000-150,000 are at risk of inheriting HD from a gene-carrying parent.

The HD Gene Marker Discovery and the Advent of Presymptomatic Testing

In a surprise breakthrough in 1983, a genetic marker was discovered which localized the HD gene to an area close to the tip of the short arm of chromosome four. This discovery paved the way for a presymptomatic test for Huntington's Disease using DNA linkage testing.

In 1986, testing for HD began on a research basis at The Johns Hopkins Hospital, Baltimore, and at Massachusetts General Hospital, Boston. Because it relied on tracing the inheritance of markers linked to the gene rather than the gene itself; the test required the analysis of DNA samples from multiple family members and was 95% accurate at best. As more and more markers for the HD gene were identified, the test became more accurate. It also became commercially available and was soon offered at over 20 centers across the United States.

The Huntington's Disease Gene

Ten years after the marker discovery, it was announced in March 1993, that the HD gene had been isolated. At one end of the gene, a pattern of three DNA bases (CAG), or nucleotides, repeats itself in all cases. In "normal" individuals, this trinucleotide, or triplet, repeat occurs between 11 and 29 times. In people with HD, the repeat occurs over and over again, from 40 times to more than 80.

In between the "normal" range of repeats and the HD range lies an intermediate "gray area." Data continues to be collected in hopes of illuminating the significance of a repeat count in this gray area. As of May 1993, a repeat count between 30 and 39 constitutes a non-informative result.

It has been shown that a weak correlation exists between the number of repeats and the age of onset, such that those having the very highest number of repeats develop the juvenile form of HD. Generally, however, this correlation is not tight and should not be used to attempt estimates of age of onset.

A Direct Gene Test for HD

As a result of the gene discovery, a direct genetic test for HD has replaced the indirect linkage marker test. The new test analyzes DNA directly for the presence of the Huntington's Disease mutation, obviating the need for collection and analysis of samples from multiple family members. However, a sample from an affected relative, preferably a parent, is usually required for the purposes of confirmation.

While the HD gene discovery alters the technical aspects of predictive testing for Huntington's Disease, there is still no cure for HD, no available treatment to delay its onset or to slow, stop or reverse the disease's relentless progression. The personal, family and ethical issues surrounding the test remain unchanged, and the importance of counseling undiminished.

REASONS FOR TAKING THE TEST

Those who choose to be tested usually do so in order to be able to make informed plans for the future regarding marriage, reproduction, career, finances, and so on. Others may simply crave relief from the anguish of being "at-risk." For them, knowing, whatever the outcome, is better than not knowing.

At-risk women who are pregnant may wish to take a prenatal test to permit the selective abortion of a fetus found to be a gene-carrier for HD. A non-disclosing prenatal test (which is an indirect RFLP test for markers close to the gene and requires multiple samples from relatives) is also an option for the at-risk woman who does not wish to know her own gene-carrier status.

Experience has shown that while many at-risk individuals indicate a desire to know their gene-carrier status, far fewer actually undergo testing. When confronted with the opportunity for testing, the majority find that the emotional toll or risks to confidentiality outweigh the benefits of learning their gene-carrier status.

The decision to take a presymptomatic test for Huntington's Disease should always be an informed, carefully considered and freely chosen personal decision. Individuals should not be coerced into testing, whether by a spouse, another family member, a physician, an insurance company or an employer.

TIMING

Predictive testing should take place during a time of low stress in other areas of life and in an environment that can provide adequate support. Except during pregnancy, testing does not involve a sense of urgency or emergency, and indeed, *should be considered in a cautious manner.*

The fact that it is now possible to obtain a test result in a few weeks rather than several months can have the effect of encouraging individuals to rush the process. However,

having enough time to really think about the implications of testing is crucial, as evidenced by the number of individuals that drop out of testing before receiving their test results.

THE IMPORTANCE OF A TEAM APPROACH

The testing program usually involves several sessions. It is recommended that the following components be included:

- Initial phone contact should include a prescreen interview with the at-risk individual.
- Three pretest, in-person sessions (genetic counseling, neurological evaluation and psychological evaluation). Reading materials should be given to participants to assure that they know about the testing procedure.
- A fourth session for disclosure of results.
- Post-test counseling sessions over a two-year period.

The introduction of a direct gene test for HD and the likely proliferation of labs offering the test will expand access to testing beyond the confines of a select group of genetic centers.

As with testing based on genetic linkage, direct gene testing will have a significant impact on individuals and their families, especially spouses and parents. Sensitivity to this fact remains an important prerequisite for testing.

Each element of the testing process outlined above is necessary for a specific reason based on current knowledge of Huntington's Disease and sound psychological principles. Experience has shown this process to be effective in minimizing serious outcomes resulting directly from testing. This should not be interpreted as suggesting that testing has little impact on those who take the test or their families. Rather, professionals with the most experience of testing, as well as people who have been tested, urge caution.

Whenever possible, physicians are strongly advised to refer applicants for testing to the nearest designated HD testing center. These centers are staffed with the personnel necessary to administer the counseling and other sessions outlined above.

CONFIDENTIALITY

Professional-patient confidentiality is governed by individual state laws. For example, in some states, although there is professional-patient "confidentiality" patient records may be subpoenaed by a court of law and must be provided. The person being tested may wish to have his or her test results classified in a psychiatric record, rather than a general medical record, as in some states this can increase the level of confidentiality of test results. The individual at risk should be aware of the laws of the particular state in which he or she is tested.

Test results should not be divulged to anyone other than the participant without the written consent of that individual. No names or identifying materials should be computer-coded. It is

conceivable that the director of a particular test site may wish to use individual findings for reports of research purposes. In these instances, identifying numbers, not names, should be used to do the test score analyses.

Only in the most exceptional circumstances, i.e., prolonged coma, death, etc., may information about the test result, if so requested, be provided to family members.

Test centers requesting a sample from an affected family member in addition to the at-risk applicant should not establish direct contact with the relative without the applicant's permission. All precautions should be taken when approaching such a relative.

THE COMPANION AND LOCAL COUNSELOR

At the outset, the testing participant should be encouraged to identify a companion—a spouse or a close friend—to accompany him or her to all of the testing sessions. Another at-risk individual, such as a sibling, may not be a good choice as a companion. Being present throughout, he or she will gain a special insight into what the participant is going through and will thus become a uniquely valuable source of moral support.

Early identification of a counselor close to home is also recommended, particularly if the person taking the test lives some distance from the testing site. The counselor may be a psychologist, social worker, psychiatrist, or another mental health professional. He or she should agree at the start to be available for emotional support and/or counseling at any time throughout the testing process, should the need arise. The counselor close to home needs to have standardized packets of information available and a consulting relationship to the testing center staff if at all possible.

PRE-TEST COUNSELING

Pre-test counseling is still considered the single most important aspect of testing. The goals of counseling are fairly simple:

1. To inform the individual about HD, including the wide range of its clinical and psychological implications, the genetic aspects, and reproductive options. It must be pointed out that neither prevention nor cure is possible at this time. Palliative treatment to provide therapy for behavioral problems, nutritional concerns, and physical therapy are available to maintain the best possible "wellness."
2. To inform the individual about his or her current level of risk.
3. To inform the individual about his or her options for testing.
4. To inform the individual of the limitations (especially the ambiguity of a result in the intermediate repeat range—the "gray area") and explain the level of accuracy of the procedure. The counselor should explain, for example, that although the gene defect has been found, in the event of a positive result, no useful information can be given at the present time about the age of onset, the kind of symptoms, their severity, or the rate of progression. In addition, while the predictive test may indicate whether someone has inherited the gene defect, it does not confirm the onset of illness when the gene is present. Onset of the disease can only be established by neurological examination.

5. To insure that the individual is aware of the potential negative consequences of testing. For non-disclosing prenatal testing only, which is carried out by RFLP linkage analysis, genetic testing may show that the putative parent is not the biological parent. It is unlikely that the direct DNA test will reveal non-paternity.
6. To insure that the individual has carefully thought through the risks and benefits of testing. If possible, testing experiences of others could be included. The implications of the testing outcome for the future, either positive or negative, should be discussed.

It is also recognized that all individuals differ, and that the person might need more or less time to achieve these goals depending on their experience, previous knowledge of testing, preparation, and number of years they have been aware of their risk. Persons having only recently learned of their risk may not have had the opportunity to fully appreciate the implications of the test, and may not have developed defense mechanisms to deal with an adverse outcome.

NEUROLOGICAL EXAMINATION

The purpose of the neurological examination is to make certain that the individual at risk for HD is not showing symptoms of the disease and is actually “presymptomatic.” Every effort should be made to distinguish the difference between a diagnosis of HD based on clinical symptoms and the finding that an individual is a gene-carrier. A person for whom a positive clinical diagnosis has been made may feel that he or she does not need testing. However, refusal to undergo this examination does not justify withholding the presymptomatic test from an at-risk applicant.

A neurological exam may also reveal soft signs suggestive of HD but not sufficient to warrant a diagnosis. In some instances, what are interpreted as soft behavioral signs, such as anxiety or depression, may not be related to HD at all. The frequency of inherited affective and anxiety disorders is considerably greater than the frequency of HD. Thus, in many instances the soft behavioral signs point to an independently inherited genetic disorder not linked to HD.

A person with subtle dysfunctions may be at slightly increased risk of being a gene-carrier or may be relatively close to more overt symptomatology. The neurological exam can provide the test facility with information about how closely an individual may need to be followed in the time immediately following the test outcome.

PSYCHOLOGICAL AND/OR PSYCHIATRIC SCREENING

Psychological and/or psychiatric screening is still strongly recommended based on the high levels of depression found in those at risk.

The risk of adverse emotional response remains the single greatest risk of the test. It is important that psychological evaluation of emotional stability not be viewed as a hurdle to be jumped in order to qualify for testing, but rather, as a method of identifying persons likely to need greater emotional support in follow-up. In some instances, such as overt risk for suicide and/or major depressive symptoms, it is appropriate to delay testing, initiate psychiatric treatment and stabilize the individual before proceeding with the test.

NEUROPSYCHOLOGICAL TESTING

Neuropsychological testing may be used in some centers as part of the pre-test evaluation. Many centers prefer to use Neuropsychological evaluations after testing to establish baseline performance and to be better able to monitor the onset of symptoms of the emergence of problems that might significantly impact functioning. This testing is often very expensive and the relative importance of the additional information to be gained from it should be considered on an individual basis.

DELIVERY OF RESULTS

Excluding prenatal non-disclosing testing or exceptional circumstances, there should be a minimum interval of one month between the pretest information and counseling sessions and the final decision to take the test. The counselor should ascertain that the pretest information has been properly understood and should take the initiative to be assured of this.

The result of the predictive test should be delivered in person as soon as reasonably possible after completion of the test, on a date agreed upon in advance among the center, the counselor and the individual.

The manner in which the results are delivered should previously have been discussed and agreed upon by the counseling team and the individual.

The participant has the right to decide, prior to the date fixed for the delivery of results, that these results shall not be given to him or her.

The results of the test should be given in person by the counselor to the individual in the presence of his or her companion. *No result should ever be given by telephone or mail.* The counselor should allocate sufficient time for the discussion of the test result and its implications and to provide whatever support may be necessary.

FOLLOW-UP/POST-TEST COUNSELING

Regularly scheduled follow-up is a necessary and important part of testing. The psychological impact of a test result—a good or a bad test result—varies considerably and is difficult to predict. Some centers have found it extremely helpful to have individuals identify a local professional support person in addition to regularly scheduled follow-up with the testing center. If an individual then finds it difficult to return to the testing center, professional support is still available.

TESTING OF MINORS

Minors should not be tested unless there is a medically compelling reason to do so, i.e., an at-risk child is believed to be showing symptoms. However, under no circumstances is testing a substitute for a thorough neurological and neuropsychological workup, for the reasons mentioned above. Parental anxiety concerning a child's risk does not constitute a medically compelling reason.

The reluctance to test minors includes situations in which prospective adoptive parents wish to have a child at risk for HD tested prior to agreeing to the adoption. Such testing is not considered in the child's best interest. Although a result indicating that the child does not carry the HD gene may facilitate an adoption (albeit one in which the adoptive parents have demonstrated less than wholehearted acceptance), a positive test may resign a child to permanent foster care.

Some professionals feel that there are no circumstances which would justify testing a minor, as the genetic test does not confirm that the symptoms are HD or not, for example, a seizure disorder in a 5-year-old. Others feel that if the biological father had onset at age 18-20, testing would be akin to testing for muscular dystrophy or cystic fibrosis, where the family knows that there is a high risk for early demise. This is an extremely sensitive area, which could even be open to litigation, i.e., a child taking a parent or testing facility to court.

There is a great difference of opinion on this issue, and centers are advised to formulate their own policies regarding the testing of minors.

CONFIRMATORY AND DIAGNOSTIC TESTING

The genetic test for HD may prove helpful in the following situations:

1. *Confirmatory testing in an individual with CLEAR SYMPTOMS of HD and a documented family history.*

Confirmatory testing by direct DNA test may be offered as an option to individuals who are given a clinical diagnosis of HD. For some individuals, the extra cost may be an issue and needs to be weighed against the information to be gained. The difference between clinically affected and carrying the gene for HD needs to be clearly explained to patients and their families. A clinical neurological examination remains the definitive means by which to determine the onset of the disease.

It should be emphasized that CLEAR SYMPTOMS do not include "soft signs" of HD when there is a family history of HD. Invoking confirmatory testing on this basis merely to circumvent presymptomatic counseling is not only a disservice to the individual, but may have severe behavioral consequences interrupting the individual's and his or her family's life, which may be more costly in the long run than the counseling process itself.

2. *Diagnostic testing when an individual presents with CLEAR NEUROLOGICAL SYMPTOMS THAT APPEAR TO BE HD, but there is no family history.*

Experience has shown that many families are either unclear or entirely ignorant about the history of HD in their family. An extensive family history should be taken. Direct gene testing can be extremely helpful in determining the differential diagnosis of movement disorders, and the fact that new mutations have now been documented, although still rare, suggests that testing is appropriate in this circumstance.

PRESYMPTOMATIC TESTING OF INDIVIDUALS AT 25% RISK *WHEN THEIR AT-RISK PARENT IS STILL LIVING*

In reality, this is a test that is very rarely requested. An adult grandchild of an adult person does not usually experience extraordinary anxiety about his or her risk when the parent is “normal.” Rather, this is most often requested when the parent is exhibiting suspicious symptoms.

Testing an individual at 25% risk may reveal information about his or her at-risk parent. The potential impact on other family members needs to be considered. For some parents, the prospect of this information is not particularly anxiety-provoking. For other parents in other families, however, the impact of this type of testing may be substantial. Professionals offering this type of testing should explore family dynamics and try to assess the implications for other family members. A consensus on testing among those individuals who are directly affected is the ideal situation, although this will not always be possible.

PRENATAL TESTING

Individuals or couples considering prenatal testing are advised to seek genetic counseling prior to becoming pregnant. Prenatal testing is usually requested in one of two circumstances:

1. The first situation is one where a prospective parent has been diagnosed with HD or has been found to be a gene carrier by genetic testing. Prenatal testing can be used to increase the fetal risk from 50% to virtually 100% or to decrease the fetal risk from 50% to virtually zero. Options for decision-making, include the option of termination should the fetus be found to be a gene carrier, should be discussed prior to testing. The potential difficulties of having a child identified as a gene-carrier from birth (expectations, discrimination, insurance problems, psychological problems) should also be discussed.
2. The second circumstance is where the parent is at 50% risk and is not showing symptoms. In this case, to find that the fetus carries the gene for HD automatically reveals that the parent is a gene-carrier as well. A very common and problematic circumstance involves an at-risk woman who is pregnant and who undergoes presymptomatic and prenatal testing simultaneously. If the outcome is positive for both tests, the impact is overwhelmingly traumatic. Prospective parents should be clearly counseled about the emotional ramifications of this potential “double whammy.” A two-step process by which the at-risk parent is tested first and prenatal testing is done second if necessary, is probably the preferred option.

NON-DISCLOSING PRENATAL TESTING

The prospective parent who is at 50% risk and who does not wish to know his or her gene-carrier status may opt for non-disclosing prenatal testing. Using linkage analysis, this test may reduce the fetus’ risk from 25% to virtually zero or increase the risk from 25% to 50%. The parent remains at 50% risk, but if he or she later develops HD, then any child or children show to have increased (50%) risk will probably also develop HD.

Since non-disclosing prenatal testing relies on genetic linkage analysis and therefore requires DNA samples from several family members, it is particularly important for couples seeking this type of test to seek counseling and to prepare for the test prior to conception. If possible, the

necessary blood samples should be obtained and DNA analysis initiated in advance of the pregnancy. Fetal DNA samples are obtained by chorionic villus sampling (CVS) or amniocentesis.

REPEAT TESTING FOR THOSE ALREADY TESTED WITH LINKAGE

Individuals should be offered the opportunity to have their tests rerun if they so choose. Informed consent for repeat testing should be sought before rerunning any samples, although some centers have already started checking previously tested samples. Offering repeat testing and obtaining informed consent avoids the possibility that an incorrect test result has been disclosed and not being able to share that information because no permission was sought.

ANONYMOUS TESTING

The advent of direct gene sampling makes it possible to determine whether a blood sample sent anonymously to a lab has an expanded number of CAG repeats. While the confidentiality of genetic test results is of great concern, anonymous testing would not increase the protection of a person at risk for HD and would pose a danger. Labs are advised not to accept anonymous samples for testing.

If national insurance with universal coverage becomes the law, then the main reason for anonymous testing will disappear.

Appendix I

Sample Informed Consent Form for the Huntington's Disease Direct Genetic Test

I would like to participate in predictive testing for the presence of the Huntington's Disease gene. I understand that the gene for HD has been found and it is located on Chromosome 4. It has been described as having a trinucleotide (CAG) repeat mutation. It is the size of this trinucleotide repeat that determines whether or not HD will be expressed. The blood test will determine the size of this CAG repeat.

I understand that there can be three outcomes to my test:

1. Negative: I will be told that the CAG repeat size is in the normal range (30 or fewer repeats), and that I am not at risk for developing HD.
2. Positive: I will be told that the CAG repeat size is expanded into the HD range (40 or more repeats) and that I will develop HD at some point in my life.
3. Uninformative: I will be told that the CAG repeat size is in the intermediate range (31-39 repeats) and that it is unclear whether I will or will not develop HD at some point in my life.

I understand that a positive test result cannot tell me when I will begin showing signs of HD. I understand that the diagnosis of the onset of HD can only be made through a neurological exam.

If available, it is recommended that this blood test first be performed on an infected family member in order to confirm the presence of HD in my family.

I agree to participate in the counseling sessions and neurological exam required for the test. Sessions will last from one to three hours. Time between sessions will vary depending upon my own desire for space between visits and the number of other people scheduled for the testing and neurological consultation. I understand that during this time I will take part in psychological evaluations, including an in-depth interview regarding my attitude towards predictive testing, how I could react to various test outcomes, my personal relationships, how I would handle these, and other aspects of psychological functioning which have a bearing on the testing procedure.

I am fully aware that my decision to seek testing in the program is wholly voluntary and that I can choose to terminate at any time without jeopardy. I also understand that the test program staff may decide to postpone my testing. The reasons for doing so will be fully explained to me.

I understand that I am encouraged to have a companion of my choice accompany me through the entire program or parts of it as I choose.

The risks of such testing are primarily of a psychological nature. A non-informative outcome can be frustrating and can intensify the ambiguity of the risk situation or can provide relief. A negative result can produce feelings of guilt as well as of guilt. A positive result, i.e., that the gene is present, could lead to serious psychological consequences including feelings of depression, futility, despair and severe stress. Counseling provided during the test is designed to help me adjust to uninformative, positive and negative information as best as possible.

Appendix II

Suggested Reading Materials

(Note: Items published before 1993 refer only to the “old” test based on linkage analysis. While these publications’ descriptions of the test may be outdated, many of the issues discussed continue to have relevance.)

Susan Ager. “The Verdict.” *Detroit Free Press Magazine*, Nov. 20, 1988.(\$1.00)

Gabrielle Hamilton, Geri Harville, Catherine Hays, Sally Spaulding, Alice Wexler. “Experiences of Predictive Testing for Huntington’s Disease.” An anthology of perspectives collected from *The Marker*. HDSA.(\$0.50)

Michael Hayden, et al.1992.“The Psychological Consequences of Predictive Testing for Huntington’s Disease.” *The New England Journal of Medicine*, 327:20(Free)

Michael Hayden, et al.1993.“Attitudes Toward Direct Predictive Testing for Huntington’s Disease Gene.”*JAMA*, 270:19.(\$0.50)

Catherine Hays.1992.“Genetic Testing for HD: A Family Issue.” *The New England Journal of Medicine*, 327: 20.(Free)

Randi Jones.1994.“Genetic Testing for Huntington’s Disease: What’s New?” *The Marker*, Vol. 7 No. 1.HDSA.(HDSA).(Free)

Nancy Wexler.1993.“We’ve Got the HD Gene! But What Does It Mean?” *The Marker*, Vol. 6 No. 2.HDSA.(Free)

Nancy Wexler. “Disease Gene Identification: Ethical Considerations.” *Hospital Practice*, Oct. 15, 1991.(\$1.00)

Nancy Wexler.1990.“Presymptomatic Testing for Huntington’s Disease: Harbinger of the New Genetics.” *Genetics, Ethics and Human Values*. Bankowski, Capron, eds.(\$1.00)

All materials listed above may be obtained from the Huntington's Disease Society of America, 158 West 29th Street, 7th Floor, New York, NY 10001.

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www.hdsa.org