

## Interactive Case for October-November 2000

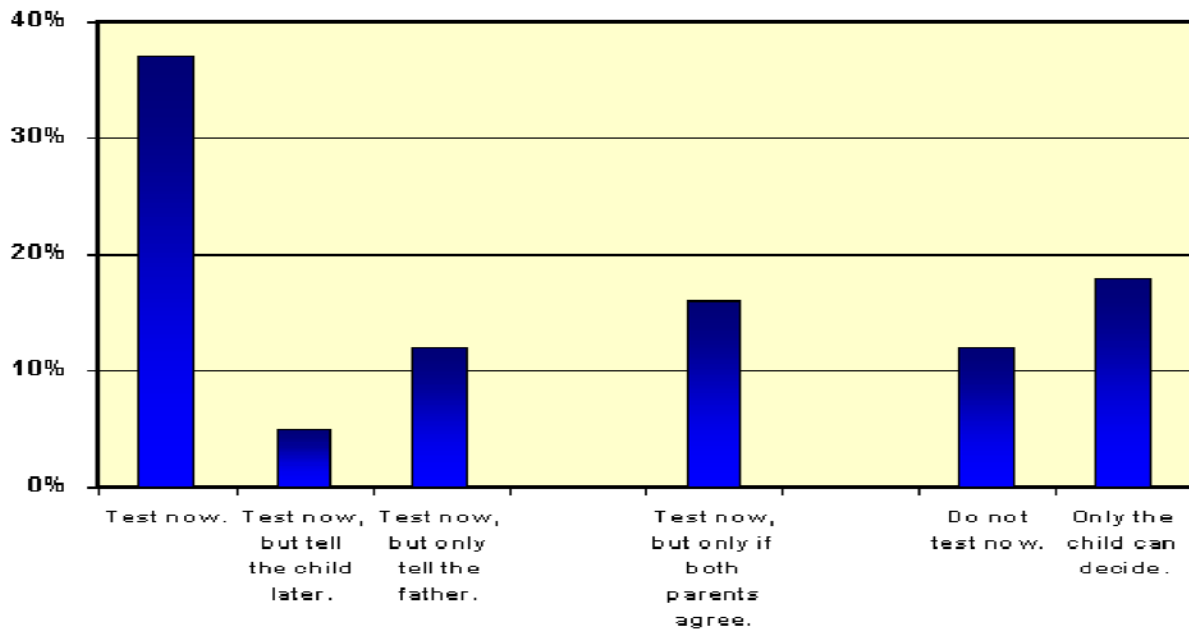
You are a genetics counselor, that is, someone who helps people understand information about their genetic makeup. A young couple comes to you for advice about their three year old son. They tell you that the boy's grandmother recently died from Huntington's disease, which is caused by a specific genetic variation. Anyone who has the variation eventually develops the disease although it usually starts when the person is in their late 30's or 40's. The rate of progression of the symptoms varies, and there are no known ways of preventing or curing the disease; it is always fatal. The father also has the genetic variation associated with Huntington's but has not yet developed any disease symptoms. Now, he wants to know about his son. He tells you, "It would help us plan for the future if we knew whether or not he will eventually get the disease. I want to get him tested." The mother responds: "I don't. I don't want to know." What do you advise this couple? What are the important ethical issues?

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Dear Students,

Thank you for your responses to the ethics discussion case for October/November 2000. We received 97 responses representing 14 schools. Your answers were very thoughtful, and you raised important points about the situation.

More than half of you (51 responses) would advise these parents to go ahead and test their child now. Of these, some said not to tell the child, and others said only to tell the father. Another large group of students (15 responses) felt that it would be all right to test the child but only if both parents agreed. Finally, the rest of you (28 students) would not do the test at this time arguing in some cases that you thought the child should make his own decision. These results are summarized in the table below.



Keep reading and you will find faculty comments regarding this case. As you will see, all three of the professional genetics counselors who read this case reached the same conclusions.

### **Professional Response #1**

Deciding whether to test this child depends on 1) potential benefits and harms of the test, 2) the decision-making capacity of the child, and 3) the counselor's duty to the best interests of the child.

The primary justification for any medical procedure including genetic testing is medical benefit. There is no medical benefit to testing a 3-year old child for Huntington disease because there is no treatment. If the child were showing symptoms of the condition, or if an immediate treatment were available, then testing would be called for. A second justification might be psychological benefit. In this case, however, the child is too young to understand the disease. The father might benefit psychologically from having the knowledge regarding his son, but this is not the same as psychological benefit to the child.

At age three years, a child does not have decision making ability so the parents have to make decisions for him. Nevertheless, the patient is the child, not the father. The counselor's first duty is to the best interests of the child. Also, even though the child cannot make decisions, he still has individual rights. As he grows older, the boy's decision making capacity will increase and at some point he will be able to participate in the decision about Huntington's Disease testing.

The parents' disagreement is another reason that testing should not be done. The father's rights are not more important than the mother's simply because the father has Huntington's Disease. On the other hand, deferring the test is not meant to take the mother's side. Testing can still be done in the future. In the absence of agreement between the parents, testing will create additional psychological stress on the family regardless of the outcome.

### **Professional Response #2**

This ethical issues in this case are commonly encountered in the genetic counseling field today.

Some of the guiding principles important in this case are respect for autonomy, confidentiality, beneficence, and informed consent. Autonomy means that we should respect an individual's right to make his own decisions such as whether or not to have a genetic test. Confidentiality means that everyone has the right to have information about them remain confidential. Beneficence means that we should strive to do good for people. And informed consent means that a person needs to understand all of the pros and cons of a medical decision before he or she makes a choice.

Why might someone want to know if they have inherited something as devastating as Huntington disease? Some things that people in this situation have expressed are:

They just need to know because they just can't stand not knowing.

They want to make financial and other plans for the future.

They want to know if they should have children.

They want to know if their children should be worried about this.

However, many people have expressed many reasons for not wanting to be tested:

They feel they may become depressed and develop poor self esteem if they get bad news.

They think other people will treat them differently.

They may be discriminated against.

They would rather live thinking that there is a chance that they did not inherit the disease.

In this case, the person we are proposing to test is the child. The child is the patient. A parent may have reasons to want him tested, but we have to look at the testing from the boy's point of view. Clearly a boy of three cannot make up his mind about something like this test; he cannot give informed consent. If his parents have him tested, then the boy will not have the ability to choose for himself whether he wants his genetic information to be known. Once he has been tested, the child will have no control over who knows the results.

Most important of all, we have to ask if we are going to do this child any good by testing him since there is no treatment that can be offered to him. Major genetics and neurology organizations around the world have said that children should not undergo genetic testing unless there is some medical benefit.

The counselor should sit down with the parents and help them understand these complicated ideas about what is in the best interest of the child. Hopefully, the parents will be able to come to their own conclusion that testing the child is taking away that extremely important option from him, and that the child himself should be allowed to make the decision to be tested or not when he is older.

### **Professional Response #3**

The counselor should spend a great deal of time trying to understand the concerns of each parent and the reasons for their differing conclusions about testing their son. What fears underlie their questions? What impact has Huntington's Disease had on each of their lives that shapes their concerns? I have no doubt that they each have nothing but the best in mind for their son, and it would be helpful for them to each hear the viewpoints of the other.

While the counselor should have respect for the parents' views, the overriding concern is the well-being of the child. Since Huntington's Disease is not treatable at this time, there is no medical benefit to knowing gene status at an early age. The promise of a potential cure in the future does not equal the need to test now. Testing can easily be done at such time that a beneficial intervention becomes available.

There are potential harmful effects of knowing at a young age of impending significant illness. Most significantly these would be of a psychological nature for the child and for family relationships, but could also include issues of employment or insurance discrimination.

Instead of testing, the child should be informed as he grows up that his grandmother died of Huntington's Disease and should be given honest information as he sees his father develop symptoms in the next few years. In this way the child will come to know that he is "at risk" (50%) for developing the disease in his adult life. Testing the child when he is still so young removes from him the possibility of not knowing later - thus interfering with his own autonomy when he grows to adulthood.

#### **More Reading**

If you want to read more, guidelines for presymptomatic genetic testing (testing before disease symptoms appear) of children and adolescents have been published by The American Society of Human Genetics and The American College of Medical Genetics and can be found on the web at: <http://www.faseb.org/genetics/ashg/policy/pol-13.htm>

### Student Comments:

November 29, 2000

I believe that the mother of this child should know whether he has the disease or not. I would really try to convince her to know the results of the test. I also think it would be good for her to know about his future health. I would also go ahead and do the test for the father. Then I would hopefully think that both parents would want to know the results.

C.-11th grade-Health Science Technology  
Hallsville High School

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November 29, 2000

I believe that the parents of this child should come to a mutual agreement in which both parents are equally benefitted. I suggest that the father be told and the mother not. First, however, I believe that the parents should be told so that they will be prepared if the boy really does have Huntington's disease.

R.-Health Science Technology  
Hallsville High School

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November 20, 2000

I think that in this case I would ask the parents to discuss it and try to come to a mutual decision. If that is not possible, I think that I would tell the father but not tell the mother and let them do what they will with the information.

S.11th grade-Health Science Technology  
North Lamar High School

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November 20, 2000

The father wants to know if his three year old son has Huntington's Disease but the mother doesn't. I would test the child for the disease and tell the father the results outside the mother's presence. If the father tells the mother the results, despite her wishes, then that is something they'll have to deal with together. I feel that by doing it this way, I would be respecting both the father's and the mother's wishes and maintaining the boundaries of the law. Anything that goes on beyond that is out of my hands.

R., 12th grade-Health Science Technology  
North Lamar High School

November 20, 2000

If I were counseling the parents , I would try to convince the mother that she should know. I can understand why she wouldn't want to know, because maybe she thinks that all she is going to think about for thirty years or until the symptoms occur, but she would probably regret not knowing.

J.-11th grade Health Science Technology  
North Lamar High School

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November 20, 2000

I would get consent from the father for taking some test and after I received the results I would call the father and schedule an appointment to tell him the results. The reason I would do it this way is because you only need one of the parents to give you permission to do a test and if the mom happened to sue it would be a hard battle for her to win.

H.- 11th grade -Health Science Technology  
North Lamar High School

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November 20, 2000

I think I would talk to the parents and try to get them to decide on whether they do want or don't want to know. Tell them to talk about it and take their time but try to steer them away from wanting to know because the child is only 3 and the disease doesn't show until your 30 or 40. It will just cause problems in the family if he were to have it. Maybe later on in life they could find out but they should wait a couple of years or so before they find out.

H.-11th grade-Health Science Technology  
North Lamar High School

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November 17, 2000

I think the child should be tested for his safety. The counselor should do what he thinks is right and the child should be tested. The mother should try to understand.

A. - Cumby High School

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November 17, 2000

I would give all relevant information to the parents and assist them in coming to a mutual agreement that will be in the child's best interests. I would also advise them to wait until the child is older and let him help make the decision to be tested or not.

D.-Cumby High School

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November 16, 2000

I think that the boy should be tested and the results should be only given to the father.

S.-Biology-Cumby High School

November 14, 2000

I think that when the boy gets old enough that you should explain to him about the disease and tell him that his father has it and tell him that he may be a possible carrier and then let him decide if he wants to know or not.

L. - Cumby High School

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November 14, 2000

I would let the boy decide for himself when he gets older.

N.-Cumby High School

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November 14, 2000

For my opinion, if this kind of disease was a genetic variation disease, it will pass from generation to generation. There are no escaping, you either have the symptoms now or later. If the father has this disease, but haven't developed the symptoms yet, he will get them later. If they want to know whether their son has this disease, they need to get their son tested to see if he was exposed or not. You have to do what's best for your child, even though there isn't a way to prevent or cure it. I think both the father and the child need to do what's best for them.

U.

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November 14, 2000

I think it is a great idea for the three year old boy to test for Huntington's disease. Although this disease is presently incurable, but perhaps somewhere down this boy's life line scientists and doctors might find the cure. Knowing that he actually contracted the disease will give him a better chance of surviving it, because most diseases at their primitive stage are easier to diagnose, the same might be applicable to Huntington's disease. Beside it is a possibility that he will not contract the disease at all. Knowing the truth isn't a bad thing.

T. -AP Biology  
Sam Houston High School

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November 14, 2000

"Mr. and Mrs. Hughes, it is to my understanding that you come here today to seek my counseling on the issue of whether or not Charles should be tested for any variation associated with Huntington's disease. It also states here that you, Mr. Hughes, supports the genetic testing. However, your wife seems to disagree with you on this issue. First of all, I would like to comment that Mrs. Hughes, you are a little bit nebulous with your answer. You say that you do not want to know, yet you do not state the reason for your standing on the issue as your husband does. Secondly, I want you both to know that I strongly believe in an individual's right to make his own decision. I think that it is unethical to make an important decision like this without that person's consent. It is obvious Charles is incapable of making this life altering decision right now, so I suggest that you both wait until Charles is old enough to make his own choice. In fact, I think the testing should be delayed until Charles is an adult himself. Mr. Hughes, you say that knowing the result will help you plan out your son's future. This does not make sense, because the disease will not develop until Charles is in his 30's or 40's. He is then already an adult. Whether you know it now

or not should not in any way affect your plans for your son, while he is still in your custody. Are you saying that if the test shows up positive, you would discourage your son from going to college or setting high goals for himself because he is going to die anyway? It is also to my knowledge that Charles's grandmother has just passed away from Huntington's disease. I am making the assumption that she is at least in her late 60's. If the disease is passed on to Charles, he still has half of his life in front of him. Depending on whether or not he pursues a healthy and active lifestyle, he really has nothing to worry about. I encourage you both to delay the testing and wait until Charles is able to make the decision for himself, because after all this is about him. You would not want to do the testing now and have him resent you for it later. It is his decision, and it is for him to choose, when he is capable of doing so."

H. 12th grade-Biology II  
Sam Houston High School

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November 14, 2000

I am a genetics counselor trying to give advice to a young couple who wants advice about their three year old son. The boy's grandmother had recently died from Huntington's disease and the father has the genetic variation associated with Huntington's but has not yet developed any symptoms. The father wants to know if his son will get the disease, but the mother doesn't. What I would do is to get the boy tested and see whether he will or will not get Huntington's disease. I know I'll be putting myself in a jam, since the father wants to know, but the mother is too scared to get him tested. It is their right to know and I don't believe that I should deny them that right. Whether I tell them or not, they'll have to eventually find out about their son. My opinion is that telling them is the best thing to do. The mother will have to come to the realization that not everything she hear is going to be good, and she can't just learn what she wants to know.

P.- 12th grade Biology II  
Sam Houston High School

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November 14, 2000

I am a genetic advisor and a couple came in and asked for advice on their son's future because their grandmother just died from Huntington's disease. The father has a variation of the symptom but has not yet been diagnose with the disease. The father want to know if his son is going to get it, but at the same time the mother do not wish to know. I think it is ethically right not to tell either one of them, because if you were to tell the father that is just like you telling the mother too, for she would have got the bad new from the expression of the father. This would be the same as telling the mother.

D., 12th grade -Biology  
Sam Houston High School

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November 14, 2000

Whether to posses the knowledge of their child's fate is an extremely difficult decision for the couple. The husband would like to know to better prepare himself and his son for the future at hand. The wife, however, knowing that the genetic disease is always fatal, does not want to know that her son will not live a full life. I understand why the wife fears the knowledge. She may be scared that her son is much too young to learn of the situation at hand. But the father has the right to know his son's future. Living with the disease may not have an effect now, but refusing to know just impends their son's future. The son has the ultimate right to know, and as he grows older he will certainly

desire this knowledge. The future may even give way to new innovations in that field of genetics, and will be able to cure the son. Basically my advice to the couple would be to test the child. I would suggest not to tell the son until he is older and when they are ready. In this case, going without knowledge is immoral for the family, the son, and their future.

V.C., 12th grade-AP Biology II  
Sam Houston High School

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November 14, 2000

As a genetics counselor, I would strongly advise this young couple to have their son tested for Huntington's's disease. Although the father has the genetic variation associated with Huntington's, the son has a 50/50 chance of actually being diagnosed for the disease. Therefore, the son may not have the disease at all, but we could never know unless he was tested. Even if the son does develop Huntington's, symptoms are usually not apparent until the late 30's or 40's. The child is only three years of age at the moment, thus, the family is still capable of living a harmonious life together until his time has come.

M. N. -AP Biology II  
Sam Houston High School

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November 14, 2000

As a genetics counselor, I would definitely recommend the couple to have their child tested, but I agree with the mother so my answer will be biased. If I did not recommend the test, I would not be a very good genetics counselor since I would be putting genetics out of business. Since I am being forced to be one, the best advice I can give is let the child decide when he is mature. Everyone on this world should have the right to choose their own path in life. Since the disease does not develop until late 30's or 40's. The father is having a find life with the genetic variation. It will not hurt his childhood. It will hurt his childhood if he does not understand the disease and the consequences. The time to have the test is the time the child is ready. They also have to consider the emotions expressed by the matured child when his father starts to show symptoms, but they have the decision of when he is ready.

L., 12th grade  
AP Biology-Sam Houston High School

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November 14, 2000

As a genetics counselor, I would advise the parents to have their son tested. For the many reasons that he would have the possibility of living a normal life and maybe also saving the lives of others. If he gets tested and he tests positive then in his later years he has the choice of taking the risk and having kids and spreading the disease to them or not. But who knows, 30-40 years from now the disease may have a cure to it or a drug that can stop but not cure the disease from getting any worse. Do keep in consideration that the child is only 3 years old at this time.

K. -AP Biology II  
Sam Houston High School

November 14, 2000

If I was the counselor, I would advise the couple to take the test. Because it is better to know now than be sorry later. Also if the boy do have the symptoms of having the Huntington's disease, it's not going to cure him by hiding it. I would tell the couple that if you take the test now, they would have less to worry about each day of their life. Even if the boy test is positive, they can have some form of process that can slow down the disease and maybe later medicine might improve and cure the disease. The point is you can't change the fate of a person by hiding the truth, rather you can face the truth. You can try to help yourself and maybe there is always room for a miracle to happen.

J. -Sam Houston High

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November 14, 2000

As a genetics counselor, I believe that the child should be tested because the disease can be prevented from getting any worse or maybe to find so later in the future when he decides to have kids he can prevent it from spreading. Maybe 30 to 40 years from now there might be a way to cure it. One never knows what is held in the future. Do keep in mind that the boy is only 3 years old. He still has a long time and in that span of time there could be a lot that is going on in the medical field that would develop a cure or some way to stop it from progressing. So just to be safe, the mother should have the child tested.

T.-AP Biology  
Sam Houston High School

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November 13, 2000

The ethical issues that must be considered is the question of "playing God". Genetic coding and technology has put science and medicine in a position where we can predict and even alter future diseases by examining ones genetic code. Even though we know that this child has a high chance of procuring this disease in his future, it is still part of his life. Considering that the rate of progression is relatively slow, with symptoms not usually occurring until one's late 30's or 40's, and that his GRANDMOTHER recently died from it, even if the boy tests positive for this disease his quality of life will not be drastically altered by it. He may still have children if he chooses to (which raises another ethical problem) since his father has this disease, and may live a normal life until the symptoms begin to develop. Therefore, this couple should get their child tested just to make sure if he has this disease. After that, they may rest easily because he will live a normal life for many years until fate taps him on the shoulder and tells him his time has come.

TNL, 12th grade -AP Biology II  
Sam Houston High School

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November 13, 2000

The saying, "Better Safe than Sorry" applies to this story very much so. As a genetic counselor, I believe the child should be tested. There might be no known ways of preventing or curing the disease now, but do keep in mind that the symptoms of the disease starts in the late 30's or 40's. The child is only three now. Technology is the key to every answer. What makes you think 30 years from now those doctors or scientist won't find some way to stop that disease from progressing? Always keep in mind, "If there is a will, there's a way". Therefore, the mother should have her child tested because who knows what technology has in store for the future. For example, AIDS, a disease that most people thought there would be no hope for. There might not be a definite cure

for it, technology has lead to medicine that can control it from progressing in the human body. There might not be a cure now for the Huntington's disease, but in the near future there will be. The mom doesn't know for sure it's incurable.

T., 12th grade -AP Biology  
Sam Houston High School

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November 13, 2000

As a genetic counselor, I would advise the parents to go for the test. I would explain to them that they should always put their son's best health interest before all else. If their son knew of the disease, he will better himself for future problems and obstacles. The ethical issue is whether or not the parents should deprive their son's right to know of the fatal disease. Although the disease is terminal, preparedness for it could mean life or death.

N., 12th grade -AP Biology II  
Sam Houston High School

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November 13, 2000

As a genetic counselor I would advise both parents to consider getting their son tested for Huntington's disease. It will be a great thing to test for the disease now. Yet, both parents does not know that their son will eventually show symptoms of the disease. And besides their son has the right to know about the condition of the disease. Later in life the parents can expect their son to be happy because of early testing and telling him the truth that he has the disease. With the knowledge of the disease their son can live happily without surprising testament by his parents that he have Huntington's Disease at the last minutes.

N.Sr.

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November 2, 2000

In the case of the couple who the father wanted to know and the mother did not want to know about their son having the Huntington's disease, I would like to give you my input. What I would say to that couple would be this:

Dear Mr. and Mrs. Smith(ex.) this is a very tough situation in which you are in. This takes a lot of time to think about. This is something that you should know, but not your son, because he will grow up knowing that one day he is going to get this disease and be sick then eventually die from it. But this is only if he has this disease in his genes. If he doesn't, then you won't have to worry about him getting this disease. You might even be able to use it as a story to tell your son. If you don't know, when he is older he probably won't know what to do if you didn't know ahead of time. If you went ahead and tested him, I could help you start looking for good doctors and try to find a cure before the disease develops. But this is your decision. If you want to take some time to think about it, I will be waiting for your call. But remember one thing, this is very important for your sake and also the baby's.

P. Jr., 9th grade Honors Biology  
Sam Houston High School

November 2, 2000

Regarding whether the couple should or should not, I say they should proceed with the testing for the Huntington disease. Why? If they don't and keep it a secret for a while the child would be kind of shocked when he's a teen. He may one day have a child (without the parents knowing) and pass the disease to the baby. So the parents should have their child tested right now to see the result. Rather be safe than sorry.

T., 9th grade  
Sam Houston High School

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November 2, 2000

I think the child should be test to see if he have the Huntington's disease or not. In my opinion I think this way because the parents could plan what to do and not to be very worry and wondering if their son have the disease. Without the test the parents don't know if the child have the disease not, then they just let everything go normally. If the parents know that the child have the disease, then they could propose him to do the thing he should do or the thing he should not do; for example, not to marry anyone. The Huntington's disease can pass from one person to another, so if the parents know that the child have the disease, then they could preventing it from spreading to others. Don't let the child know if he have the disease because he will feel differently and ruin his purpose of life. Help him to enjoy his life.

P., 8th grade -Pre-AP Biology  
Sam Houston High School

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November 1, 2000

I don't think that the father should be able to know about his son, because it would only make it harder for the family if he knows he will get the disease as he grows older. Not only will the father have to deal with knowing and not being able to tell his wife, he will eventually have to tell his son. If he will not get the disease, they would eventually find that out anyway. As for planning for the future, I don't believe that it would effect anything if they knew or not. Their son should be able to live a long productive life even if he is going to get the disease some day. I would advise them to make him aware of the possibilities of one day developing the disease, but they should continue to treat him as a normal child. They should go ahead and plan for college as if they knew he would go for sure. If the symptoms don't come until his 30's or 40's, he should be able to live life just fine until then.

B.I., 12th grade-Anatomy & Physiology  
Bastrop High School

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November 1, 2000

It would be really horrible if you know your son would die in his 30-40s. But do you want to risk not telling him the truth? The truth hurts but we must all say it. I think he should go through some tests to determine if he has the disease. This would enable you and your son to plan ahead as the father opinionated. It is necessary to know unless your son may get married and pass on the genes. Which may even cause a world disaster.

O., 11th grade-Biology  
Sam Houston High School

November 1, 2000

I can't say that I would definitely know how to react to this situation, since I am not a parent. From where I stand, I think it would be a good idea for the child to get tested. The parents can keep looking for updates in the progress of learning more about this disease and if there are any possibilities of treating, preventing, or even curing this disease. If the child should be tested positive for the disease, the child has a right to know, but that doesn't necessarily mean that the child cannot have a happy life.

Q. -Pre-Ap Biology  
Sam Houston High School

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November 1, 2000

I personally think that the child should not be tested for Huntington's disease. The parents already know that the boy has a chance of getting the disease, why make it harder for them? Most people would say yes, he should be tested so they can all be prepared for the future and not be shocked. But if they know he has a chance of getting it, shouldn't they be prepared for it already? If they find out that he's proven positive, it would spoil everything and live everyday knowing their son can get Huntington's disease. What if he gets the disease? By that time, he is old enough to deal with it himself. If he finds out now, he would feel depressed and ask himself what's the use of living if he know he's going to die. It just makes people pity him, like going around asking if he's okay or not.

C.-Pre-AP Biology  
Sam Houston High School

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November 1, 2000

I would advise the couple to have the child tested. I feel this way because if they did not have the child tested, how would they go on through life knowing that their child possibly posses this fatal disease. I don't know truly how I would react to this subject, but I would like to know if MY child had a fatal disease. I would like to know what would happen to my child so I could prepare for the future. What if, hopefully not, but what if the child does indeed have this disease, the tests would only show that the disease is present in the child. Whether or not the tests are taken, the disease would still be there. In the same way, if it were possible that you, hopefully not but if you were exposed to A.I.D.S., wouldn't you want to ascertain if you would test positive for A.I.D.S.? I would want to know. If my wife did not want to know, then I would find out myself and not react in any way that she would know the outcome of the tests for the disease. If the child tested positive, I would tell them not to tell the child until he was around 15 years or so because then he should be old enough to handle what he has. Telling the child while he is still 3, is just un-heard of! He's too young to understand and to comprehend death that he would not live a happy full life. So go ahead, have the child tested! Hopefully by God's Grace the child will not have this genetic disorder. Amen. But if he does, all you can do is pray for strength, and that soon a cure will be found.

S.-Pre-AP Biology  
Sam Houston High School

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November 1, 2000

As a genetic counselor I would advise the couple to test their son to see if he has Huntington's disease so that they can plan for his future and not live the rest of their life worrying about whether or not their son will die or live. I would tell the father first and let him tell the mother when she is ready to know the truth. With this knowledge they can tell their son the truth as soon as he gets old and mature enough to understand the situation he is in. On a lighter note, if he gets tested and the

results turn out to be negative the parents can live a happy life and not worry about their son's life. Either way, being tested would have two results that can be worked with throughout their son's life.

L., 10th grade Biology  
Sam Houston High School

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November 1, 2000

I think the parents should have the son tested just like the dad suggested. If not, then the parents would always be worry if their child would have the disease. For some reason that Huntington's disease infect the child, I would advise them not tell there son. I think no one wants to know if they would have a disease that cannot be cure. How would they feel? But the parents could help him make his life to be complete for a short period of time, I also agree with what the mother was thinking. Why do you want to take a test to know if the child have the disease or not? Like I was saying, no one want to know if they have a disease that cannot be prevented. Why don't they just let it go normally and stop worry about it? I know how they feel, but if they know the boy have the disease, they probably would be more worry than when they're not sure if the son have the disease or not.

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November 1, 2000

I think the parents should not request the test for their son. If they did not request the test, the parents partly think that the child would not have the disease and would not worry very much. For example, if they have the test for the child and discover that the child has the Huntington's disease, they probably will feel very bad, not excepting what they have known. They won't be able to tell their son that he have a disease that cannot be cured because they're afraid that the son would not be happy with his life and do something that they won't expect him to do.

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November 1, 2000

Even though the parents are both concerned with their child in two opposing ways, I would have to agree with the father. Being the genetics counselor, I would have to explain to the mother and father why it is best to take the tests for their child. The main reason for the test is that if their child does indeed have the disease, the child would be able to prepare for his life. When he develops the characteristics of Huntington's disease, it is extremely important that him and his family understand that it is caused by the disease. That way they would not fret over the involuntary actions because they do not know what is happening. If he is diagnosed with the disease, it does not mean that he should live his life in a different way. His parents would have to let him enjoy every minute of life and feel positive so that when he dies at his early age, he wouldn't feel as though he wasted his life isolating himself from the world and obsessing over his condition. However, it would also be very important to allow the child to decide whether or not he wants to be tested when he is mature and old enough to understand what kind of situation he is dealing with.

T. -Pre-AP Biology 1<sup>st</sup>  
Sam Houston High School

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October 31, 2000

If a couple comes to me for advice about the dilemma concerning their son having the Huntington's disease or not, I would advise them to take a test. Even though it is a disaster for a mother, I agreed with the father. Taking the test also takes the burden off the parent's chests because they would never be happy and would never stop being anxious until they learn the truth. Their son is only three years old, he might not understand, he's innocent but that doesn't means they have the right to keep him from knowing the truth. They can't keep the secret away from him forever. He has a

lot to look forward to, a bright future awaits him but the fact is he has a good chance of having this illness.

As for the mother, I'm too young to really understand what it is like to be "a mother", to give birth and nurture another human. A human being that you care for, that you love, that means the whole world to you, hoping that one day he'll grow up to be someone worthwhile. Suddenly, a stranger comes up to you and tells you that your baby is carrying a deadly disease, that he would die in his 30's or 40's? It must feel like an invisible hand reaching through your chest and pulls out your heart then tears it apart. Wouldn't you rather want to know what might happen in the future, now, than to face it unexpectedly later? Who knows? Maybe after taking the test, he turns out to be all right and normal. Don't give up hope yet.

A.T.-Pre-AP Biology 1<sup>st</sup>  
Sam Houston High School

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October 31, 2000

1. If he has the disease then you can plan his future accordingly. He should be told about this at a later age. Right now the child doesn't need to worry about when he is going to die. His life shouldn't be limited to certain things because the symptoms aren't present. He should just go through his life and enjoy it. The parents need to discuss, when they think he is old enough to understand his condition. Just because he is going to die, doesn't mean he should stop going through life.

2. If he doesn't have the disease there shouldn't be much to worry about. If he doesn't have the disease his life should be lived normally. If he has siblings get them tested for the disease.

D.-Sam Houston High School

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October 30, 2000

I would advise the couple to test the child. They would find out if the child was infected with the disease, and would be able to make sure the child could live his life to the fullest. The child would have at least twenty years to enjoy life. In the mean time, science might progress to the point where they would have a cure for it. If the boy knew all his life that he was going to die early, then he could accept that and go on, but if he didn't have the disease, then he could live his life normally, and his parents wouldn't have to live with the fear that he might die soon. Either way, the child would have some or all of his life to live happily. It could be the parent's decision to tell the child.

J.L.S.

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October 30, 2000

I think the father is right. I think they should know what is going to happen to prepare for the future ahead. If the mother doesn't want to know, just let the father talk to the genetics counselor and let him find out the information. You never know, you could find out good info. I think it's always best to know especially if they're dealing with a fatal disease.

W., 12th grade-Sanger High School

October 30, 2000

I would advise the couple to decide on their own first before asking for assistance. If the child is a carrier of the disease, they have the right to know, but they also have the right not to know. The decision must come from the both of them. When the child comes of age, he may choose on his own. But until that point, both parents must decide.

R.-Sanger High School

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October 30, 2000

As a counselor to the parents of this child, they need to be made aware of the probability of his carrying the genetic variation. Due to the certainness of the final outcome and the fact that it rarely shows symptoms before adulthood, what would be the benefit of testing. The child needs to be able to enjoy a normal life as he grows but should be made aware of the genetic history of his father and ancestors. He would have the opportunity to make his own decision about being tested. I would advise both parents to be just that, parents, and enjoy everyday as if it were their last. As for the father's desire to plan for the future, that is great. He has the knowledge he needs to do this without the testing. Plan to raise your child into a healthy, caring and productive adult and then let him make his own decision about testing.

C., 10th grade  
Sanger High School

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October 30, 2000

I would advise the couple to think it over and come to a conclusion that suits both of them after looking at the good and bad of each side. Ethical issues that they need to consider are what would be the best for the child. Having him tested may cause him to worry or think more about the disease. It also might change your whole life.

M., 10th grade  
Sanger High School

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October 30, 2000

I don't think they should test the little boy. I think they should leave it to fate because there's not a cure for it yet. If he was tested and the results came back positive, I think that the family and the son would all get worried and the boy would have to live with the fact that when he turns about 30 or 40, he is going to get a disease and die.

C., 10th grade  
Sanger High School

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October 30, 2000

I would tell them that they probably need to know about their son. They should know if he has the disease so they can plan for the future. They won't be surprised in the future if they find out now.

J., 11th grade  
Sanger High School

October 30, 2000

1. Seek help together on whether or not to test the child.
2. Explain that your job is to help people understand information about their genetic make-up not to recommend testing for their son.
3. Offer the father your services in understanding his genetic make-up.
4. Offer the mother information on Huntington's disease.
5. Offer any other assistance you can offer.
6. Don't influence people's decision.
7. Don't take sides, remain objective.

K., 10th grade  
Sanger High School

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October 30, 2000

I think that they should not find out whether or not he has the gene. If the disease is fatal and there is no way of preventing or curing the disease, then why know. The father says that if he knew, it would help them plan for the future. What is he trying to say? Why would he want or need to know when the son is only 3 years old? I think the mother is the one in the right because she doesn't want to know.

B., 10th grade  
Sanger High School

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October 30, 2000

In this situation, I would want to have the consent of both parents. This is a complicated dilemma, and to make an educated decision in this case, you must think of the factors involved. The father wants to test his son, but the mother does not. If the father wants to find out about whether or not his son has the disease, he needs to work out an agreement with his wife. I would choose not to test otherwise because of the consequences that may ensue.

A., 12th grade-Anatomy & Physiology  
Azle High School

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October 30, 2000

The main ethical issue of the matter is the agreement between both parties of the couple, they first should decide as a whole whether they want to know or not. Personally, I think that it is best for the parents to know whether he has the disease or not for the sake of future planning. Whether it be him having or not having the disease, it will be easier for them to know in advance. If he should happen to have the disease it would be best for the family to have some sort of a counselor or psychiatrist for the family. They also should wait until they feel he is at a reasonable age to tell him that he has the disease. Until then, they should encourage him to live his life to the fullest and they should just enjoy their lives with him, even if it is short.

A.Biology  
Sam Houston High School

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October 30, 2000

I would like to express to the genetics counselor what I think about this particular situation and what this person should do. One of the choices I am considering to do is to tell the young couple about their son's condition and what to expect in the near future. I think that it is an important thing to classify and establish to the family about what is going on. If my job was as a counselor, I would feel obligated to tell the father, what he wants to know and not to condone his thoughts. If the mother's desire is not to know if her son has the genetic variation then it is my priority to only concern her husband with the information about their child. I assume that soon she will want to know about her son too. Because she is a mother and if she truly cares for her son, she would give in to the truth about her son even if the results are bad. I would have to say to the couple that it would be better for them to know now about their son because in the end they will find out even if they don't want to recognize the situation that their son is in. I can tell by the mother's decision, that she is very naive about what to do if her son does have the genetic variation. She demonstrates that she doesn't want to identify that it is true and that it could be possible for her son to be consumed with this fatal disease. Her husband is ready to withstand the worst to come. He understands what is going to happen and I can see that he wants to help his son overcome his fear of dying if there is any, at the right time. But who knows, maybe a cure will be found and this disease can be prevented by antibiotics. This is what I would do if I was to come to a doctor, counselor, etc. that this situation pertained too. I would also like to say if I was the couple with the problem and if I was the father, I wouldn't want the physician's consciences to effect the details I was suppose to be informed with about the most important thing in my life.

D.-Biology

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October 30, 2000

I think this couple needs to consider several things including:

1. the cost of the testing
2. whether the test will be painful for their child
3. if he tests positive for this disease will they be able to give him treatment or medicine to help the symptoms.

Since their son is only 3 years old if they found out he would have the disease they might decide to put him in a special home for sick kids. I don't think this would be a good idea because he is their child and he belongs with his parents. It doesn't say that the parents would ever tell their son if he would get the disease. If I had the choice of knowing whether or not I would get a terrible disease when I'm older I would not want to know because I would always be worried thinking about it.

R., 9th Grade -Physical Science  
Harwood Jr. High

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October 30, 2000

The advise that I would suggest would be for the parents not to get their son tested, for Huntington's disease. The main reason for this recommendation has to do with the psychological effect of knowing and its effect on the people involved. For instance, if their son had the disease, the parents would have the burden of breaking the terrible news to their child. Once the child is informed that he has the disease, he is faced to live the rest of his life knowing he would be deprived of a full life. This could have serious negative effects. Depression may set in, causing the boy to lose all perception of the meaning of his life. He could think, what is the point of aiming for anything when you know that you will not live to see the fruits of your labor. There will always be the anxiety of dying early in the back of his mind, therefore making it very hard for him to live a normal life. This

is also where the ethics issue comes in. The main question comes back to whether it is fair for the child to be robbed of the precious years he could have enjoyed. If he never knew whether or not he had the disease, he could live with hope. Hope and anticipation are key motivators in life. In conclusion, I believe that not knowing is the best way to go, holding the child's best interest at hand.

R., 9th grade Honors Biology  
Sam Houston High School

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October 30, 2000

I believe that the young boy should be able to make his own opinion on the subject. Since he is 3 years old, he should grow up living a normal life but when he is mature enough or old enough, his parents should inform him of the possibility that he may have Huntington's disease. Then he should make his choice of whether he wants to know how his life is going to turn out. Plus, the fact that he may die at an early age should not help the parents plan his future. His life should not be affected because of the fact that he might get the disease. If he tests positive for the disease, he should still live his life like any normal child, adolescent, or adult.

M., 9th Grade-Pre-Ap Biology  
Sam Houston High School

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October 27, 2000

I would advise the parents to give their child the test. If the father and the grandmother both have the disease the chances are that so does their child. It would probably be a better idea to get an outlook on their child's life and to explain to the kid when he is born that he does have the disease.

M.-Cumby High School

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October 27, 2000

I would advise you take all precautions before deciding whether to test the child. I think that the child should be able to grow up a normal life and when he is old enough, tell him the situation, and then let him make the decision.

J.-Cumby High School

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October 27, 2000

I would advise the parents of this child to wait until the child is old enough to decide himself mainly for the reasons that the child should make his own decision when it could tell him whether he's going to die or not. Another reason is there is no cure, so it does the parents no good to know this early because there is nothing they can do but wonder why and be sad. This is what I'd do in this position.

R.-Cumby High School

October 27, 2000

I believe that the parents should work together along this situation. But for my opinion I think that they both should go along with the testing for their son's sake, just in case he does have the symptoms of this disease. So that they will be able to know what to do when the symptoms get worse! And it would probably help them financially and mentally, so they will know what their in for when they have to go to the doctor.

A., 10th grade  
Navasota High School

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October 27, 2000

In my opinion he should be tested for the disease. If he is tested then he will probably have a better chance of living if he does have the disease because they will give him medicine for the disease. If they don't test him, then he could have it and die sooner than he would if they knew. But if he is tested he may not even have the disease. It would be better to know, than to not know.

T., 10th Grade  
Navasota High School

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October 27, 2000

I believe that the parents have a very difficult decision to make. They need to ask the son if he wants to know if he has Huntington. I think they need to find out soon if he has it. It may be better for the son's future and they will be prepared for what might happen.

J., 10th grade-Biology

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October 27, 2000

I believe that those parents have a very difficult decision to make. Determining their child's fate is almost unnatural. As a person grows older, the fact that you will die comes easier to accept. I believe that they shouldn't take the test while their child is so young. If the child is showing no indications that he is in harm, than there is no need for any tests. As the boy grows older and he comes to understand life better then perhaps he can make the choice to take the test to see whether or not he has the disease. If the parents were to have the test taken and the results are not good, the child may be missing out on the chance to live a normal life. If I were put into the situation that those people were put into I wouldn't have the test taken.

R.-Biology  
Navasota High School

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October 27, 2000

After reading the situation, I have concluded that there really is no earth-shattering ethical obligation on anyone's part. As a genetics counselor, I have a responsibility to alert my patients to any harm that may threaten them. I would advise the parents to run the test on their child to find out if he has the genetic variation for Huntington's Disease. I have many reasons for doing so, but here are two.

1) The father is right, even though his "planning for the future" might seem vain. I have noticed that people have highly valued their childhood. Many don't get a happy and memorable one. Testing the child would not, in any way take away from his childhood because a) if he does have the genetic variation, the father can ensure him a good childhood. and b) if he doesn't have the

variation, then the father who does have it, can make sure that his child spends a sufficient amount of time with him (paternal relationship).

2) The child is a CHILD. Let's remind ourselves that he WON'T have any symptoms until he is in his 30's or 40's. As previously stated, the child will lead a normal and happy childhood, either based on his having the disorder or his father's. Now, the mother seems to be scared. Who wouldn't? But I think that she, deep down, knows that her son has the disorder (even though he might not). But, her fears should not prevent the father and ,eventually, the child from the truth. I think that the mother doesn't realize that we are talking about her SON. He might be diagnosed with a shorter life, but nevertheless, a LIFE.

As a genetic specialist, I see no harm in testing this child for the genetic variation. Either he has it or he doesn't. Nothing can be done about it (maybe in the future, though). If the child has the disorder, his parents will be ready to give the best of life to him. If he doesn't, then I believe that the parents will still do the same because of the father's situation. So, I believe that the parents should not just test their child, but MUST do it.

A., 10th Grade-AP Biology  
Dunbar High School

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October 27, 2000

In life there are always two choices, always forks in the road. Everyday we make choices, some monumental, others minuscule. For the parents of that genetically mysterious child, they must make a choice also. Either they can "test" for the child and determine his future at the ripe age of three, or they can leave aside till he is old enough to make a decision on his own. The latter, is my advice to them. Ignorance to some extent is bliss. If the parents do run the tests, then they will lead lives of hiding, and aberrancy, in the way that they treat their child. However, if they do not run the tests, then the parents and the child can lead lives of normalcy, yet still with dubious minds. To me it seems, that decisions like these lie in the hands of the direct victim, which is the child. This is the ethical issue in this case. Also, it would be better off for the child, if the parents wait to see if the father has the disease. This in turn will decrease the monetary debt they will be in if the tests are conducted. So, if looked at closely, conducting the tests will only bring suffrage and sheltered life to the child. It is just better to wait and see what the future holds. Motherly instinct always prevails.

C., 11th Grade  
Dunbar High School

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October 27, 2000

In the case presented, since he is not asked, the genetic counselor should not get involved in the ethics, but rather, present to the parents the facts on an objective basis. However, if he were to make a suggestion to the parents, then he should tell them to test the child. This suggestion could be made, however, assuming that the parents would be unbiased towards the results, which they should be since, even if the kid is tested positive for the disease, during the time that he is under the parents' custody, he will not be affected by the disease in any way. The father makes the statement that it would "help [them] plan for the future if [they] knew whether or not he will eventually get the disease." I do not see how he can make such a statement since they will certainly never be planning for the future of the child once he reaches an age of 30-40. This statement by the father possibly shows that they may not be able to handle a positive result to the testing in the correct manner, but if the genetic counselor were to make it clear to them how to treat the child in the worst possible scenario, I think that the parents may at least try to be unbiased. The reasons for having the child tested are obvious. Knowing the results of the test would clear up the ambiguity of the child's future, which is much better than not having the child tested, regardless of whether

or not the child has the disease. This may be hard to believe, but if you think about it, once a punishment is known, it is not as scary as one that isn't known. An example is seen from school where, if one gets into trouble and receives detention, he or she will most likely not mind that much. But this punishment is made much worse when the teacher tells him or her to go to the principal's office, because this time, what will happen in the end is not known. Other than just knowing the child's fate, testing the child can give valuable evidence about the disease, and possibly even lead to a cure for it. The child won't be afflicted by the disease until he is 30-40 years old, and in that much time, technology can be enhanced enough to find a cure for his disease. We have already seen how far technology can go in only 10 years, especially in the medical field. As for being treated "differently" by others, who said the kid or his parents have to tell anyone he has the disease? If being left out because of a "handicap" (although he won't have one while he is in school or college) is a concern, then he can easily refrain himself from making his disease public knowledge. The only concern I see in this case, if the child is tested, is by the parents' reaction to it. The mother chooses not to know, and ignorance is always a choice. She does not need to see the results of the test, but the father should certainly have a right to know his child's distant future, although he will most likely not be able to do much about it.

S., 10th Grade-A.P. Biology  
Dunbar High School

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October 27, 2000

I would advise the couple to get the son tested. They should tell their son when he has grown up and is mature enough to accept it. The mother is afraid that her son will grow up in fear of his death, but if it were me, I would like to know. It might be hard for the son to accept the fact at first but after a while he will have to come to terms with it. If I knew that I would die in my 30s, I would live my life to the fullest and be prepared for my death. I would make peace with myself and my family and with God (or whoever he believes in). That way I know I'll have a better life in heaven.

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October 27, 2000

I think that in the best interest of the child that the boy should wait until he is about 18 years of age to be tested. It would work out best for all parties involved. This would allow him adequate time to prepare for the future.

J.-Cumby High School

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October 26, 2000

This is actually a simple case. There are several scenarios:

1. Either the son has the genetic anomaly that will cause the disease, or he does not.
2. He can either be tested at this time or not.

If he does not have the disease, then it really does not matter whether he gets tested or not. Thus, we must assume that he does have the disease. In other words, we must assume the worst case scenario.

1. If he is not tested then the parents are simply neglecting their responsibility. As parents they must make sure their child has everything available in their power in order to survive, and lead the most fulfilling life possible. They may not be able to cure his disease, but they can do what they can up until the child is old enough to make his own decision. Then, at least he knows his parents cared enough to do what they could before he was old enough to make his own decisions. If I were that child I would be infinitely thankful to them. The indisputable fact is, the parents must get him tested,

because it is their JOB AS PARENTS to do so. The mother in this case is simply being selfish, by only caring about how she feels.

2. If he is tested and the parents find out he will die eventually, then subconsciously they may limit his life. Deep inside they will be thinking something like, "Well, he is going to die soon, so it really doesn't matter if. . ." I know it sounds cruel, but I've seen it happen-- even to people who do not have fatal diseases. When the child finds out, he may in turn adopt his parents' mind set, especially if they do not support whole-heartedly a more optimistic point of view. This scenario means death while living, which in my opinion is worse than any death.

3. However if the parents decide to carry on strongly, and support their son-- not allow self-pity to take over, and not allow frustration to take over them; then the son is still capable of leading a productive life-- no matter how short. Who knows, perhaps with his efforts and support, a cure may be found that can help him in time-- if not then others.

As a genetic counselor, I would delineate these scenarios to the parents. Allow them to make a decision, but suggest that personally, I would chose scenario #3.

M., 10th Grade A.P. Biology  
Dunbar High School

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October 26, 2000

Death is only a part of living."There is nothing gained in testing for Huntington disease in this case, except a life full of misery and sorrow if tested positive. The child's life would become ruined, forever. His entire purpose for life, and morals would totally be altered. He would probably have very few friends and practically be secluded from everything normal kids do. Why not live life happily, rather than worry about death every second? That is simply torture. Kids should run around and engage in playful activities, not sit around all day, curious about when Death will come and take them away. Obviously, I agree with the mother in this case. Of course, the father does have a right to know, however, if I were making the decision between knowing whether my child had a fatal, non-curable disease or not, I would rather not know, for I would want my kid to live a normal, happy life.

A., 10th Grade-AP Biology-P.L.  
Dunbar High School (Fort Worth)

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October 26, 2000

Each parent has the right to know as much or as little about his or her son's genetic makeup. However, he or she cannot limit how much the other parent knows. In this case, the mother does not wish her son to be tested because she doesn't want to know whether he has the variation for Huntington's. But this should not keep the father from having their son tested and finding out about any variations. The father mentioned, "It would help us plan for the future if we knew whether or not he will eventually get the disease." There isn't much to plan for -- if the son doesn't have the variation, then the family will lead a "normal" life; if he does have the variation, he won't show signs until his 30's or 40's. And then, his parents will not be responsible for him -- the planning will be up to the son. The father has the variation for the disease -- perhaps more important than planning for the son's future (for which the son will be responsible if he does have the variation, since he will be an adult before symptoms develop) is planning for the future because HE has the variation and will develop symptoms sooner than his son. The father has the right to have his son tested, just for his knowledge. There is no need to plan for the future based on whether their son has the variation. (The father, since we know he has the variation, could participate in studies to help further research on Huntington's disease.)

S., 10th Grade-AP Bio  
Dunbar High School (Ft. Worth)

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October 26, 2000

I think that they should wait until they come to a unanimous decision; it would be no good otherwise because someone will get upset. The doctor couldn't just simply tell the father because he would react to the information, whether it is good or bad. I would want to know because it would prepare me for what will come. If they wait, they can think it over and maybe come to a decision. They might want to wait until their son gets mature enough and ask him what he wants.

J. Pre-AP Biology 1  
Sam Houston High School

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October 26, 2000

In this situation, the parties involved would have to come to some sort of agreement or compromise about getting their son tested before any sort of decision is made. The doctor has a tough choice to make because he has a mother who doesn't want to know, and a father who does. The result of this testing may be good or bad, which can result in negative consequences from the mother if it is the latter of the two. I would choose to test the child, but I would leave it up to the father to tell his mother the results.

A., 12th Grade-Anatomy & Physiology

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October 26, 2000

I strongly feel that the child should get tested right away. The doctor should explain that to the parents. They have to realize how important this situation is. What the parents don't know could affect their child's future. What is the difference if the child doesn't take the test and if the child does take the test? Ask yourself, why do people even get tested? So they can prevent the future from happening or so they can cause a less severe output. There are a thousand reasons that their child should take the test. There are no reasons why he shouldn't.

K., 11th Grade Health Science Technology II  
Longview High School

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October 26, 2000

In this particular case, the genetic counselor must not let his own held ethics get the best of him while giving his advice and must remain strictly professional. Even if the counselor's opinion is held in regard, he should not have any real say on the situation. Despite the mother's doubts on the matter, I more so understand why the father might want to know the fate of his son. Knowing that he himself already has the genetic variation associated with Huntington's Disease, a genetic disorder that leads to losing control of one's muscles, the father wants to be knowledgeable of his son's future and needs to know that his son won't live his same fate. If the parents do not choose to take this critical step in their son's future and leave things to be, then in the 30, 40 years that the parents remain unknowing of whether or not the disease is to take effect, preventive methods could be developing which the parents failed to acknowledge prior to the disease being for certain (assuming the child does in fact develop Huntington's Disease). By testing, the parents will be able to prepare financially, but more than that, then and there they may be able to cope emotionally (whether that is possible or not, I don't know). In fact, if the tests are performed and they yield negative, then how big a burden off their shoulders is that? Yet, before any good can be done, both parties must come to a mutual agreement. The mother must realize that fearing the outcome of the

tests will only further intensify her fear if the disease does take effect.

V., 10th Grade-A.P. Biology  
P.L. Dunbar High School

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October 24, 2000

I think that the doctor in this case obviously has a hard decision to make. You can't really decide on your own whether or not to do the test because you know that in the end it is the parents decision. I know that as a doctor I would be frustrated in that I wouldn't know whether or not I was going to be able to perform the test. I think that the test should be performed for the well-being of the child. Doing this test now may allow for treatment to be done to lengthen the life span of the child even if he will die from it eventually. As a parent I would like to know that my child didn't have the disease, but it is up to the parents.

M., 11th Grade  
WHS HOSA

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October 24, 2000

Obviously the doctor in this situation is put in the middle of this family. I, personally, would wait until the boy reached an age that he could fully understand what was going on and make his own decision. After all, it's him that this disease is going to effect. I know it is the parents responsibility to take care of him but if this disease is going to effect him when he's in his 30's or 40's then he will be grown and on his own. So, like I said, it should be up to the boy.

J.

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October 24, 2000

In this case, the doctor is obviously put in a position in which he cannot (or rather should not) answer. The father would like to "look into the future" and alter what is already pre-destined. The mother, on the other hand, does not want to know and wants to leave without hearing anything from the doctor. I, for one, must agree fully with the mother in that knowing what the future of their child is pointless. What information is gained will not aid in saving the child (per say) but will only inform us that the child has the variation for Huntington's disease. By the couple knowing the fate of this child, they are only going to treat him differently and let the child know he is "different". Death is a part of the cycle of life and cannot be avoided. The ethical issue at hand is obviously not whether the doctor should get involved here (although I feel he shouldn't) but whether modern science should tamper and try to alter what is going to happen anyway...especially when there is no cure. Let the kid lead a normal life!!! Don't let this knowledge of his death alter the way he SHOULD be treated. In conclusion, I believe that the genetic counselor should not make the decision for the couple and should tell them that it is a decision to be made by the couple, that he is only there to do this if both the mother and the father want to know what is going to happen. If the couple still persists, I would suggest the counselor refer them to someone that can help them make the decision.

N. A., 11th Grade-AP Biology  
P.L. Dunbar High School (Fort Worth)

October 24, 2000

The genetic counselor has a difficult decision to make. I believe that he/she should go ahead and advise the couple to go forth with genetic testing. The reason for this is simple: knowing exactly what is going on and understanding the truth is vital for success. Having a dark cloud of uncertainty will always be detrimental. A free mind is necessary. Plus, as the father mentioned, it is necessary for planning. Knowing what to do always helps in any tough situation. Moreover, the parents should look optimistically at the issue. With all the genetic advancements made by government and private institutes, Huntington's patients may receive treatments to a certain degree in the next few years. The child may not even have the disease at all. This would make not doing the genetic testing even worse. Of course, several issues are involved. If the child tests positive for Huntington's, his overall future will remain bleak. But the parents should still remain optimistic for a treatment. They may, if they desire, not even tell the child of the situation. So at least they will know without devastating the child himself. But the parents must realize the day of truth for the child will come, and they must be prepared for it, or the decision to proceed with genetic testing right now will be ruled out.

A., 10th Grade-AP Biology  
Dunbar High School

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October 24, 2000

The case in question does not seem very difficult at all to me. While the mother may not want to know, the father still has a right to know and his right must be supported. If the mother does not want to know the results then she does not have to be notified of them. Others have said, "Why test when there's nothing you can do about it?" Well, this child has 30 or 40 years before he is threatened. Starting now and lasting until he does or does not show symptoms, he can participate in experimental studies and treatments. Even if this child is never cured, several decades of data can be invaluable to anyone studying genetic diseases.

C., 10th Grade-AP Biology  
Dunbar High School

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October 24, 2000

This is indeed a difficult situation. I believe that you cannot take a view of one parent over the conflicting view of the other parent. Therefore, the immediate course of action would be to tell the parents to make an unanimous choice before you begin your testing. However, with the situations of the disease, I think you should not find out now if the child carries the variation of Huntington's disease. Since, the disease does not show up until the person's thirties or forties, there is really no planning for the future on the parent's part. I believe the parents should inform the child that he might be a carrier of the disease. When he becomes an adult, he should be the one deciding if he should be tested. Some people would view knowing they had the variation as a burden, losing possibly thirty years of their life. These people would rather not know they had a deadly disease lurking in their future and let nature take its course. On the other hand, many people would rather want to know if they carried the variation to better plan for their future life. In any circumstance, it makes no immediate difference whether or not the parents know now.

J.-Biology II AP  
Kaufman High School

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October 23, 2000

At first glance, this situation is extremely hard to make a decision about. There are many factors to put into consideration. First of all, the father would like to know about the presence of this disease to plan for the future. However, people that develop this disease are usually 30 or 40 years old before they even produce symptoms. This means that the little boy would not even be living with his parents anymore; therefore, what planning does the father have in mind? Since there is a possibility of the boy never contracting the disease, test results could give the parents unnecessary fears. Also, results of the disease testing will not provide any outcome other than knowledge of the possibility of death. There is no cure, control, and no stages that could be treated when first discovered as there is with other diseases, such as cancer. The common knowledge of this disease is only up to the parents discretion - it will neither help nor hurt the boy in any way. Therefore, as the counselor, the advice to the couple should be reference to another counselor that could help them with their inability to compromise. The couple should make a list of pros and cons and come to an agreement before the genetic counselor can do anything. It is not the genetic counselor's decision whether to tell the couple or not. It is the couple's mutual decision that the counselor must abide by. Also, informing only one party will cause problems between the couple when the spouse figures out the situation.

J., 12th Grade-Anatomy & Physiology  
Azle High School

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October 23, 2000

In a situation where the parents don't agree such as this you have to have them reach a unanimous decision before you can do anything. You may want to try to tell the mother that there may be nothing wrong with the son and this may help ease her mind. But on the other hand you could tell her that if the test results in her son having the disease it may help the family prepare for the inevitable if they know. Maybe by the time her son starts showing signs of the disease there could be a cure, but if the son doesn't know he has the disease he can't cure it. If this does not seem to convince her then I would recommend that they go to counseling and try to reach a unanimous decision.

H., 11th Grade-Anatomy  
Azle High School

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October 23, 2000

In this case, there are two different sides you have to take into consideration, that of the father and the mother. Both sides have logical and valid points; but it is not the physicians choose to make. If I were to go ahead with the testing the mother would feel as if she had been betrayed by both parties; but if they chose not to go with the testing, I would feel obligated to tell them it is always better to prepare for the future and urge them to discuss it further. If I was in this position I would strongly suggest that the family seek counseling, or for the parents of the boy to set down and discuss with each other their opinion on the matter of testing for the gene the boy probably possesses. Both of these are simple solutions to a difficult situation. The consent of both parents is top priority no matter how you view this case. In any case the family still has time to decided if they wish to go on with the procedure, or they could wait until the boy is older and go with his decision of whether he wishes to be tested or not.

B., 12th Grade-Anatomy and Physiology  
Azle High School

October 23, 2000

This would be a hard decision to make. I feel that the result of the test would be of more use to the family than the 'peace of mind' they might get from not knowing. I would take the couple and try to explain the benefits of having the boy tested. Being able to make preparations for the future and being certain about the health of the child far outweigh not knowing. But when discussing this with the parents I would make sure to keep their emotions in mind. What made them ask now? My guess would be that the father has just recently found out about his disorder. This, of course, would be upsetting to him and his life's partner, and bring about concern for their son. The father, trying to except his fate, has begun making preparations while the mother, not wanting anymore bad news, just wants time to cope. Luckily, unlike many other diseases, time makes little difference in this situation. Ultimately, I would push for the test to be taken, however I would also like to make sure the family is emotionally stable enough to handle any outcome.

D. , 12 Grade-Anatomy and Physiology  
Azle High School

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October 23, 2000

This is a tough case. On one hand you have the father who wants the testing done and on the other you have the mother who doesn't. I believe that before any testing is done, there needs to be a decision made between the parents. If the parents cannot decide whether or not to get the testing, wait a few years and let the child decide. Since the disease usually doesn't take effect until the patients are between the ages of 30 and 40 years old, it will not hurt the child to make the decision himself. Then the physician doesn't have to worry about making any mistakes and the parents don't have to worry about arguing.

J., 12th Grade-Biology II  
Kaufman High School

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October 23, 2000

There are many factors that need to be greatly considered in this situation. First of all, the parents need to be informed that their son only has a fifty percent chance of inheriting this disease. I would then explain that, more than most disorders, Huntington's disease exacts enormous emotional, physical, social, and financial tolls on EVERY member of the patient's family. The next thing I would do is refer them to some type of physiological, clinical or marital counseling to explain to them every aspect of Huntington's disease. They need to come upon an agreement between the two of them before any tests are done. After they decide, whatever needs to be done, can be done accordingly.

C., 11th Grade-Anatomy & Physiology  
Azle High School

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October 23, 2000

First, you need to advise the couple to come to an agreement. In this, they should consider that they could have him tested but only reveal the information to the father who wants to know as long as his way of preparing does not involve telling his wife. The mother does have the right to not know because she can't prevent this, only prepare. She could consider that if her husband truly wanted to find out he could and still refrain from telling her. You should suggest to have them come back after 2 months to give them more time to think between the two of them. You have the responsibility, as a physician, to test him once you have consent from one guardian.

S., 11th Grade-Anatomy  
Azle High School

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October 20, 2000

In this situation, the first step for a physician to take is to get an agreement reached between the opposing cases. In order to come to a completely satisfying decision, one must analyze the entire dilemma sequentially to reach a logical solution. If one did go ahead and do the testing, the mother would be upset and offended because one didn't respect her opinion. Simply put, the first advice would be to receive the consent of both sides to either test or not test. If the couple decides ignorance is bliss, then both the child and the couple would live blindly until symptoms show up, if any appear at all. If the couple decides to do testing, the physician must reassure the couple that knowledge overpowers all, and knowing whether or not the child has the disease can only help them. But one must also look at the possibility that he might not even have the disease, and also reassure the couple that it's not a 100% possibility. The ethical issues involved in this particular case are strong, and if the parents of the child do not agree, it is NOT up to the physician to make the decisions for the couple when both of them are there and could be easily resolved with a little counseling. Time is on your side in this instance, so use it well.

A., 11th Grade-Anatomy & Physiology  
Azle High School

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October 19, 2000

I understand the mother's concern and reason for not wanting to know if her son was going to contract the disease, but I do think that the boy should be tested. It would be wrong for a person to grow up not knowing that he could possibly die when he is only 30 years old or sooner. I would ask the mother to think into the future of when her son has a wife and kids and how they would feel if their husband/father died suddenly. I think maybe after she saw the whole picture she will choose to do the right thing by testing her child.

North Side High School, 9th Grade  
Intro to Health Science Tech (IHST)

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October 16, 2000

This is a complicated situation in which many factors are relevant. You have to respect the wishes of all parties involved, but because the parties are divided, the problem enlarges. One of the factors is the actual disease, and the relevance of the father's argument. Knowing the future may help them prepare better than being led blindly. The mother's state of being should also be a factor. Her emotions might be taking control of her thoughts and she might not be thinking clearly, or, on the other hand, she could be thinking perfectly. In this situation, I would suggest counseling of some sort. Both parents could explore each other's reasoning, and hopefully come to a consensus. Without their agreement I would not be able to test the boy. While I understand the father's thinking, I would not want to be responsible for any grievances the parents feel. I would just hope they come to a mutual decision.

A., 11th Grade-Anatomy & Physiology  
Azle High School

October 16, 2000

This case is not as rare as you might think. Recent developments such as the genome project have revealed several similar genetic aberrations associated with disease "downs syndrome" and other similar types of genetic "cases". Recently gene therapy has shown promise for correcting the symptoms of these diseases. The need to know is genuine and should be researched. Recent uses of "fetal tissue" have helped alzheimers patients—but this provides another ethical issue

R.

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October 13, 2000

In this situation, I believe it would be wise to go ahead with whatever tests needed to determine if the child has the disease. In confidentiality, I would tell the father the results, then leave the rest up to him. This way if the child has the disease, he can prepare himself for the inevitable and take advantage of every opportunity with his son, and if the son is free of the disease it will give both parents peace of mind.

T.-Azle High School

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October 12, 2000

I believe the parents need to come to an agreement on whether they want to know or not. I believe I would side with the father. If you knew in advance you could start planning emotionally and financially for the situation.

G.