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## MODERATOR

Good morning everyone, thank you so much for coming today.

Concerns have been raised recently that strides that specialists are making in prenatal genetic testing are leading us down the path of eugenics.

Eugenics, of course, is the theory and practice of human improvement by way of genetic manipulation to produce desired traits in a child. If history is any indicator, there is cause for alarm where ethics issues and eugenics are concerned.

Eugenics played a clear role in the Nazi "master race" project and the extermination of millions of people who did not meet Nazi criteria. Can the mistakes of the past be avoided? Doctors and legislators need to be open-minded and willing to hear all opinions on this topic.

Today we are talking specifically about a blood test used to screen for Down syndrome during the first trimester of pregnancy.

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## DR. WILLIAMS

The genetic test in question gives us the ability to identify Down syndrome in the womb without causing any harm to the fetus through the use of a simple blood test.

Down syndrome can bring with it a lifetime of pain and frustration which, in addition to the potential for physical abnormalities, can include a loss of cognitive ability, respiratory problems, heart defects, and more.

This test is extremely low risk and almost 100% accurate; there is no reason to view this as ethically questionable.

Giving parents this information in advance means parents have more options in general, and an opportunity to raise a healthier child.

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## **DR. GARCIA**

Obviously there's more to it than that, Catherine. For starters, many children with Down syndrome develop into healthy adults who do not suffer from the health conditions you mentioned.

And many of those potential conditions can develop independent of the syndrome, in the general population. As there is no cure for Down syndrome, the "opportunity to raise a healthier child" you refer to implies aborting a child after a positive blood test.

By promoting this test, aren't we stepping into a grey area where we are engineering human improvement based on a subjective evaluation of what is a "better" human being?

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## **MODERATOR**

Dr. Garcia, we have a question from the audience for you: I know there's no cure, but how long do people with Down syndrome typically live, and what is their quality of life?

## **DR. GARCIA**

Advances in medicine have improved life dramatically for those with Down syndrome. True, most still live shorter lives on average than those without the disorder, but many now live to be 60 or older. In the United States, many people with Down syndrome complete high school, and some go on to college. People with Down syndrome can work, volunteer, and vote. And they are able to give and receive love like everyone else.

## **MODERATOR**

Thank you, Dr. Garcia.

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## **DR. WILLIAMS**

We are not telling parents what to do with the information we give them. We are simply identifying a potential health hazard. This test is a medical advance, plain and simple. Previous tests for Down syndrome were not as accurate, and required withdrawing amniotic fluid, which came with substantial risks. This is a basic blood test. We are identifying a clear health risk. It's non-compulsory, and the benefits are strictly for greater health.

## DR. GARCIA

Perhaps not "strictly". The test will inevitably lead some parents to abort a child whose test is positive for Down syndrome, but who would not have developed any of the health problems potentially associated with the disorder.

A healthy life would have been prevented in favor of another life with more culturally accepted aesthetics, and little more. Making this test available is also making decisions about which lives we value as a society, and with that we are stepping beyond the realm of health care. This is the reason that some of us fear that these tests are leading us as a culture toward eugenics. The blood test for Down syndrome is a medical advance, but that does not mean it is an ethical advance.

## **MODERATOR**

OK, we have a question from the audience--  
What is the pregnancy termination rate after  
a diagnosis of Down syndrome?

Dr. Garcia?

## **DR. GARCIA**

Statistics vary widely, but following a prenatal  
diagnosis of Down syndrome, 60-90% of  
expectant parents choose to terminate the  
pregnancy.

## **MODERATOR**

We have a question from the audience for Dr. Williams: How rare is Down syndrome?

Dr. Williams?

## **DR. WILLIAMS**

The CDC estimated the frequency of Down syndrome in the United States as 1 in 691 live births in 2011, up from 1 in 1,087 in 1990.



**A.** Dr. Williams is correct. A mandate to either keep a child or to abort it after a diagnosis would be an entirely different discussion, but this is merely a blood test, and it is optional. We are simply providing the expecting parents with more information about their unborn child. As Down syndrome can cause significant impairment and increased health risks, we are acting ethically as health care providers in making the test available to all.

**B.** This issue is deeper than it might at first appear to be. Down syndrome can cause health issues, but the disorder itself is not unhealthy. It is just a condition that comes with a greater risk for some health problems. Since eugenics, in any form, is often rightly associated with Nazi Germany, let's look at it in that light. What if a similar test were available in Germany in the 1940s? The Nazis would have aborted the children, and might have deemed the parents no longer fit to bear children, and sterilized them. And for what? A condition that people can live long, healthy lives with.

**C.** They are both right. It is a simple blood test, and it is ethical in and of itself, but we do need to consider the ramifications of making such a test universally available. We also need to consider the message it sends about Down syndrome. Perhaps the path to take here is to make the test available as part of a battery of tests, and to provide information about Down syndrome that lets parents know what to expect if they decide to keep a child shown to have the disorder.

**D.** We should not be looking for Down syndrome at all. It is not, in and of itself, a health issue. There are health risks associated with being an Ashkenazi Jew, such as the potential for Tay-Sachs Disease, which are horrible and lethal. These are clear health concerns, and yet we would never say it's wrong to be an Ashkenazi Jew unless we truly learned nothing from World War II. This should not even be on the table for discussion.