The process is similar to what you did for the first genetic testing article - read the article and use the template below to summarize what you read. Please bring a copy of this sheet with you to the seminar discussion. You do NOT need to print out the article unless you want to do so.

1. **WHAT ARE THE THREE MAIN POINTS OF THIS ARTICLE?**
   
   A.
   
   B.
   
   C.

2. **HOW WAS GENETIC TESTING USED IN THIS ARTICLE?**

3. **WHAT WAS THE MAIN ETHICAL ISSUE DISCUSSED BY THIS ARTICLE?**

4. **WHAT ARE TWO THINGS THAT SURPRISED YOU AS YOU READ THE ARTICLE?**

We will be sharing this information with others in class next week.
Lying in the darkened doctor's office, Kate Hoffman stared at the image of the 11-week-old fetus inside her on the ultrasound screen, a tiny ghost with a big head. It would have been so sweet, Ms. Hoffman said, if something had not been so clearly wrong.

Ms. Hoffman's first three children had been healthy, and she was sure this one would be, too. She was not planning to have the amniocentesis procedure often used to test for fetal health problems, preferring to avoid even the slightest risk that the insertion of a needle into her uterus would cause her to miscarry.

But when her doctor told her there was a new way to assess the chance of certain abnormalities with no risk of miscarriage -- a blood test and special sonogram -- she happily made an appointment.

The result, signaling that the child had a high chance of having Down syndrome, thrust Ms. Hoffman and her husband into a growing group of prospective parents who have learned far more about the health of their fetus than was possible even three years ago.

Fetal genetic tests are now routinely used to diagnose diseases as well known as cystic fibrosis and as obscure as fragile X, a form of mental retardation. High-resolution sonograms can detect life-threatening defects like brain cysts as well as treatable conditions like a small hole in the heart or a cleft palate sooner and more reliably than previous generations of the technology. And the risk of Down syndrome, one of the most common birth defects, can be assessed in the first trimester rather than waiting for a second-trimester blood test or amniocentesis.

Most couples say they are both profoundly grateful for the new information and hugely burdened by the choices it forces them to make. The availability of tests earlier in pregnancy mean that if they opt for an abortion it can be safer and less public.

But first they must decide: What defect, if any, is reason enough to end a pregnancy that was very much wanted? Shortened limbs that could be partly treated with growth hormones? What about a life expectancy of only a few months? What about 30 years? Or a 20 percent chance of mental retardation?

Striving to be neutral, doctors and genetic counselors flood patients with scientific data, leaving them alone for the hard conversations about the ethics of abortion, and how having a child with a particular disease or disability would affect them and their families. There are few traditions to turn to, and rarely anyone around who has confronted a similar dilemma.
Against the backdrop of a bitter national divide on abortion, couples are devising their own very private scales for weighing whether to continue their pregnancies. Often, political or religious beliefs end up being put aside, trumped by personal feelings. And even many of those who have no doubts about their decision to terminate say the grief is lasting.

"It was never even anything I had considered until I had the bad results," said Ms. Hoffman, who ended her pregnancy last year after a follow-up test confirmed that her child, if it survived, would have Down syndrome. "It was the hardest decision I ever had to make."

She and her husband, Drew, of Marblehead, Mass., decided that the quality of the child's life, and that of the rest of their family, would be too severely compromised. "I don't look at it as though I had an abortion, even though that is technically what it is," she added. "There's a difference. I wanted this baby."

Whatever they choose, couples find themselves exposed to judgments from all sides. Several of those interviewed asked that personal details be withheld because they had let friends and family believe that their abortion was a miscarriage. Others say they have been surprised that even conservative parents, who never faced such decisions themselves, have counseled them to abort rather than face too hard a life.

Activists for the rights of the disabled say that a kind of grass-roots eugenics is evolving that will ultimately lead to greater intolerance of disabilities and less money for cures or treatments. And even some doctors who perform abortions are uncomfortable as some patients choose to quietly abort fetuses with relatively minor defects.

No one tracks the number of abortions performed for medical reasons, but obstetricians say several factors are most likely contributing to a growth in their frequency, including broader availability of new screening technologies and more pregnancies among women over 35, who are at greater risk of carrying a fetus with chromosomal abnormalities.

About a dozen tests for genetic mutations that could cause diseases or disabilities in a child are now regularly offered to pregnant women and their partners, depending on their ethnicity and conditions that run in their families.

More than 450 conditions, including deafness, dwarfism and skin disease, can be diagnosed by testing fetal cells, with more than 100 tests added in the last year alone. African-Americans are widely screened for sickle-cell anemia, and a panel that now includes nine tests for diseases common to Ashkenazi Jews has virtually eliminated the birth of children in the United States with Tay-Sachs, a fatal early childhood genetic disorder.

Next month, the Baylor College of Medicine plans to introduce a pilot program with perhaps the largest panel of prenatal tests ever offered. For $2,000, a pregnant woman will be able to have her fetus tested for some 50 conditions that cause mental retardation.
Quest Diagnostics, a leading provider of medical tests, said prenatal and genetic mutation tests were one of the fastest-growing parts of its business.

''People are going to the doctor and saying, 'I don't want to have a handicapped child, what can you do for me?''' said Charles Strom, medical director of Quest's genetic testing center.

A Couple’s Choice

The new screening tests provide reassuring news for the vast majority of pregnant women. But Amy D., a preschool teacher in Livingston, N.J., who terminated a pregnancy after finding out the child would have cystic fibrosis, remembers falling to her knees in the schoolyard when her genetic counselor called her with the test results.

She and her husband did not know what cystic fibrosis was and had no known family history of the disease, which causes progressive lung failure and carries an average life expectancy of 35 years. But in the fall of 2001, the American College of Obstetricians and Gynecologists recommended that a blood test for the gene mutations that cause the disease be offered in all pregnancies when either the man or woman is Caucasian.

Amy D. screened positive as a carrier in August 2002, shortly after she found out she was pregnant with her first child. When her husband also turned out to be a carrier, there was a one-in-four chance that their fetus would have the disease. An amniocentesis showed that it would. Having watched her husband shrink from scenes of suffering, whether in movies or during his own father’s illness, she said she knew her marriage would not survive having a severely ill child. ''My life would have been caring for my child, which would have been fine if she would be O.K.,'' said Amy D., who asked that her last name be withheld for fear that anti-abortion activists would harass her. ''But she wasn’t going to be O.K.''

After months of depression, she said she is thrilled to be adopting an infant boy from Asia. Still, when she watches the 20-something woman with cystic fibrosis on MTV’s ''Real World'' dating and getting body piercings, Amy D. says she cannot help wondering if her daughter, who would have been named Sydney Frances, would have been like that -- at least for a while.

With the number of American couples being tested to determine if they carry cystic fibrosis soaring from a few thousand in 2000 to several hundred thousand last year, more people are tackling similar decisions. Sometimes, the gene tests can even distinguish between a mutation that causes a mild form of cystic fibrosis and one that is more severe.

Kaiser Permanente, a large managed health care organization, said that when both members of a couple among its patients in Northern California tested positive, 80 percent opted for the follow-up test of their fetus. Of those whose fetus was affected, 95 percent terminated the pregnancy.

''It’s a crummy disease, the treatments are far from what we would like, and we have a reliable test,'' said Dr. David R. Witt, director of Kaiser’s Northern California prenatal screening program. ''Based on the response, people are grateful they had an opportunity to take advantage of it.''
A Slippery Slope

The wider range and earlier timing of prenatal tests are raising concern among some bioethicists and advocates for disability rights who argue that the medical establishment is sending a message to patients that the goal is to guard against the birth of children with disabilities.

"By putting them out there as something everyone must do, the profession communicates that these are conditions that everyone must avoid," said Adrienne Asch, a bioethicist at Wellesley College. "And the earlier you can get it done the more you can get away with because you never have to tell anybody."

Some doctors, too, say they are troubled by what sometimes seems like a slippery slope from prenatal science to eugenics. The problem, though, is where to draw the line.

Dr. Jonathan Lanzkowsky, an obstetrician affiliated with Mount Sinai Hospital in Manhattan, described one woman who had been born with an extra finger, which was surgically removed when she was a child. Her children have a 50-50 chance of inheriting the condition, but she is determined not to let that happen. Detecting the extra digit through early ultrasounds, she has terminated two pregnancies so far, despite doctors' efforts to persuade her to do otherwise, Dr. Lanzkowsky said.

Other doctors said that they had seen couples terminate pregnancies for poor vision, whose effect they had witnessed on a family member, or a cleft palate, which they worried would affect the quality of their child's life.

In an extreme case, Dr. Mark Engelbert, an obstetrician and gynecologist on the Upper East Side of Manhattan, said he had performed an abortion for a woman who had three girls and wanted a boy.

"She was much more comfortable with it than I was," Dr. Engelbert said. "I told her if it was a new patient I wouldn't have done it. But my feeling as a physician was that I've accepted the responsibility of being her health care provider. She's not doing anything illegal, and it's not for me to decide."

Perhaps the hardest cases for both doctors and patients come when technology provides enough information to raise concerns about the health of a fetus but not enough to make a conclusive diagnosis. When Tom Horan and his wife learned in April that their fetus's legs were bowed and shortened, they were told that the condition could be healed through braces, growth hormones and surgical procedures in childhood.

But before they decided what to do, a closer examination by a specialist with a 3-D ultrasound machine revealed other deformities: the left arm was missing below the elbow, and the right hand was only partially developed. Moreover, sometimes such features are a sign of a neurological impairment, the doctors told them, but in this case it was impossible to tell.

"Our main concern was the quality of life that the child would have growing up with such extensive limb deformities, even in the absence of cognitive problems," Mr. Horan said. He and his wife, who
have three other children, were reared Roman Catholic and had never considered terminating a pregnancy. Yet even his father, Mr. Horan said, who had long been opposed to abortion, supported their decision to end the pregnancy.

"'Confronted with this question and knowing what we knew, it changed his mind,'" Mr. Horan said. "'It's not just a question of right and wrong; it introduces all sorts of other questions that one has to consider, whether it is the survivability of the child, quality of life of parents, quality of life of siblings, social needs. And it becomes much more real when you're confronted with an actual situation.'"

After the termination, an examination showed that if he survived, Mr. Horan's son would have had an extremely rare condition, Cornelia de Lange syndrome. He would have been severely mentally and physically disabled.

The news was a relief to Mr. Horan, who said he felt sadness and grief, but no regrets about the decision. But before the diagnosis, he said, he felt guilt and uncertainty. At 21 weeks, the fetus was not viable when his wife underwent induced labor and delivery but survived briefly.

"'Our son lived for three hours, and I spent almost all that time holding him,'" Mr. Horan said. "'I worried that I had decided to rob him of his life simply based on limb deformities. I wondered about the ethical implications of taking a life simply on that basis. What did that say about me?'

Contradicting Beliefs

That is just one of many questions that couples ask themselves as they confront the ethics of whether to abort a fetus with disabilities. But because it is such a charged subject, many are loath to discuss it with others. They say there is often no outlet for their grief.

"'I cannot turn on the computer any day without getting an e-mail from someone who needs help,'" said the woman who runs A Heartbreaking Choice, an Internet support group for people who have terminated pregnancies because of their fetus's health. "'But nobody's talking about it. Certainly not here in southeastern Virginia,'" where anti-abortion groups are so vocal.

A nurse practitioner in New Jersey said her parents, in-laws and best friends all believed she had a miscarriage. In reality, after having an amniocentesis because she was 39, she discovered that the male fetus had two X chromosomes in addition to a Y chromosome. Men with the condition, Klinefelter's syndrome, have little body hair and feminine features. Some lead normal lives, but others have learning difficulties and virtually all are sterile.

"'We didn't want to put ourselves in the position to be judged, because it was difficult enough as it was,'" she said, though she said she wished she had told her family about the diagnosis. "'I was thinking about Klinefelter's constantly, but I couldn't mention it to anyone.'"
Dr. John Larsen, chairman of the department of obstetrics and gynecology at George Washington University Medical Center, said the sense of taboo was amplified by how often people's choices contradict their previously held beliefs.

"Peope will come into my office in tears and say they've been against abortion their whole lives," he said, "but they'll make an exception for themselves."

Parents of children with Down syndrome, Dr. Larsen said, also come to him for a test called chorionic villus sampling, or C.V.S. Similar to an amniocentesis, the procedure is less widely used because it carries a slightly higher risk of miscarriage, but it can be performed as early as nine weeks -- for many women, well before their pregnancies are apparent.

"They want it kept a secret," Dr. Larsen added. "They don't want their friends in the Down Syndrome Society to know that they got tested and would abort or did abort if it was positive. They'll say, 'I love my child with special needs, but I can't handle two.'"

Some parents are trying to avoid both abortion and disease by opting for in-vitro fertilization, even if they do not need it to conceive. A new procedure can test embryos in the petri dish for chromosomal abnormalities or a genetic condition known to run in a family.

That is how Sara and Benjamin Porush of Chicago came to have their 21-month-old triplets. After their first son was born with familial dysautonomia, which causes difficulty breathing and swallowing and a shortened life, the couple, who are Orthodox Jews, had 16 embryos tested for the disease, 9 of which had the gene mutations for it. Ms. Porush was implanted with three of the others.

But some couples who terminate pregnancies for fetal health conditions say no one has a right to judge them. A child psychologist in Atlanta who terminated a Down syndrome fetus earlier this year said she was outraged by people who told her, "If you have to have a perfect baby, you shouldn't be a parent."

"I was like, 'What!?'' said the psychologist, who is 35. "I've always been pro-choice, but now I'm pro-choice with a vengeance. Don't tell me I have to have a baby with Down syndrome just because you say so."

And Cristy Hollin of Gladwyne, Pa., is unapologetic about having invasive procedures to test fetal cells early in the two pregnancies that followed the diagnosis of her first son's condition as fragile X mental retardation. Neither fetus tested positive for the condition, but if they had, she said, she and her husband had planned to have an abortion.

"You love your child," said Ms. Hollin, who was told that the best she could ever hope for her fragile X son, who is now 11, was that he could one day read well enough to take a bus on his own. "But the fact is it's really, really hard. When we went to have our other kids we said we'd be fools not to know everything we can."
Factors in Decisions

Doctors and genetic counselors say the new reproductive decisions hinge on a complex equation that includes patients’ perception of disabilities, their financial situation, their ethical beliefs and their desire for a baby.

A recent study of the first-trimester screen for Down syndrome found that only 6 percent of women in Utah who tested positive for a high risk of having a fetus with the condition went on to find out definitively with an amniocentesis, said Dr. Mary D’Alton, chairwoman of obstetrics and gynecology at Columbia University Medical Center, who led the study. By contrast, at Mount Sinai in Manhattan, more than 90 percent chose to have the follow-up test.

Age can also play a role. A 44-year-old woman with her first pregnancy may look differently at an imperfection than a 23-year-old who has two children, said Dr. Ilan E. Timor, director of the ultrasound division of the obstetrics and gynecology department at New York University Hospital.

'I have seen patients with relatively minor anomalies as far as I’m concerned who don’t care and terminate the pregnancy,' Dr. Timor said. 'Then you see the other end of it, patients that have pretty major anomalies and don’t want to terminate. Every patient has a dilemma that is measured by personal needs.'

When Dondakay DeMaria, 27, and her husband, Andrew, of Campbell, Calif., who work at the same Silicon Valley technology company, both tested positive as cystic fibrosis carriers, Ms. DeMaria was sure she wanted to have an amniocentesis, and perhaps terminate the pregnancy. But after much soul-searching, the couple, who describe themselves as pro-choice, decided not to take the risk of miscarrying in order to find out the status of their fetus.

'There’s a lot of kids born into the world that have severe problems and that doesn’t stop them from having a life or having a lot of love to give,' said Mr. DeMaria, citing his adult cousin with Down syndrome as an example. ‘If my aunt and uncle would have terminated that pregnancy we would never have known Suzie.'

Some critics of the new culture of prenatal testing argue that it is causing needless anxiety for the vast majority of couples whose babies will be perfectly healthy. But some women say the new tests actually make them less anxious. Ms. Hoffman, who terminated her pregnancy last year after the first-trimester screening test alerted her to the risk of Down syndrome, is now pregnant again. She was sure she would have an amniocentesis this time, despite her fears of miscarriage. But when she went for her screening the doctor said her risk of an abnormality had fallen from one in 43 to one in 351, odds that were good enough for her.

'It took me a long time before I was ready to risk getting pregnant again,' Ms. Hoffman said. ‘And that time period couldn’t have gone fast enough before I could have my test.'