

Your Genes, Your Choices:

Exploring the
Issues Raised by
Genetic Research
by Catherine Baker

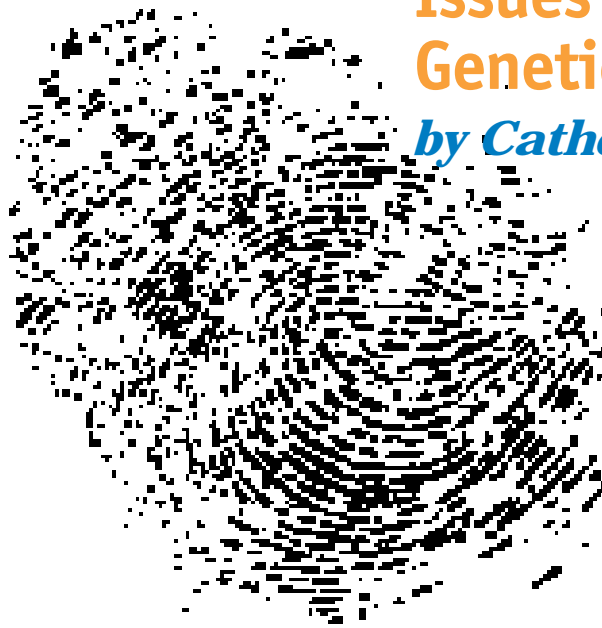


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Acknowledgments

I am not a science writer by trade. In order to write this book, I first had to study up on genetics and the issues involved. Then I had to try to explain them in a way that other newcomers to the subject could understand, without making terrible errors. It was a difficult task!

I am therefore indebted to the members of the AAAS Advisory Panel (listed on page 82). At an all-day meeting in the spring of 1995, they steered me away from my original outline toward the book you find here. Many months later, several panel members provided very useful reviews of the manuscript. For this, I would like to thank Ruth Allen, Jeffrey Botkin, Ron Cole-Turner, Robert Cook-Deegan, and Joan Weiss. From the AAAS, Mark Frankel, Jerry Bell, and Shirley Malcom provided detailed critiques, as did Daniel Drell of the Department of Energy's Human Genome Program. Dr. Drell and Dr. Cook-Deegan are to be thanked especially for their painstaking reviews of the second draft. Finally, my colleague from the literacy field, Mike Fox, provided a "plain-language" edit that seemed excessive when I first saw the pen marks, but proved on the mark, as usual.

It should be noted that in addition to the publications cited in the bibliography, the *Washington Post's* coverage of this fast-changing topic assisted my genetics education. I also looked at *Science* and *Human Genome News* (which were useful when I could understand what I was reading). The web site maintained by the Hereditary Disease Foundation helped me pin down the proper words in discussing hereditary disorders. The web site of the Center for Bioethics (in particular, the articles posted by Arthur Caplan, Mary B. Mahowald, Glenn McGee, Mark Philpott, and Antonie van den Beld) suggested issues to include in this book.

Finally, I thank Maria Sosa for her brilliant idea that the world needs an easy-to-read book on issues in genetics.

Although many people have guided my steps, I assume all responsibility for any errors and out-of-date information and for any sections in which I failed to make things clear.

Introduction

by Maria Sosa

Your Genes, Your Choices describes the Human Genome Project, the science behind it, and the ethical, legal, and social issues that are raised by the project. This book was written as part of the Science + Literacy for Health project of the American Association for the Advancement of Science (AAAS) and funded by the U.S. Department of Energy.

AAAS has a strong commitment to science literacy and the public understanding of science. Through its Directorate for Education and Human Resources Programs, AAAS has been a leader in identifying and meeting the needs of underrepresented groups in science. Science + Literacy for Health fits into this vision of making science accessible to everyone.

Most people think that science is remote from the work they do, the lives they lead, and the decisions that they make day by day. Nothing could be further from the truth. *Your Genes, Your Choices* points out how the progress of science can potentially “invade” your life in the most direct ways, affecting the choices you make at the grocery store, your own health care and that of your family, and even your reproductive decisions. The connection between science and health is a direct one, and your ability to understand the science behind health affects your ability to understand the issues and the stakes.

Science may seem difficult, because scientists often use technical language to talk about abstract ideas. This book has been written to introduce you to important ideas, but also to convince you that you can understand the basic concepts of science and that it is important to do so.

Most people are curious about the way their bodies work (and the ways they sometimes don't work very well). This curiosity goes beyond immediate concerns about any specific health condition. We hope that *Your Genes, Your Choices* helps to feed that interest.

Shirley Malcom

Head

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Science + Literacy for Health

Chapter 1

Martin Needs Medical Treatment (or does he)?



Martin came home from school the other day with a black eye and broken glasses. Another boy had called him a freak and punched him.

Martin is **albino**, which means that his skin has no color. He is very pale and his hair is white. His eyes are pink and he doesn't see very well.

Martin's mother loves her son very much just the way he is. But when she sees other children tease him, she wishes he were not so different. If he weren't, then perhaps he wouldn't be picked on so much. It makes her wonder why everyone can't be the same.

Do you ever wonder about this yourself? If it were up to you, would you want everyone to be alike?

The world is filled with nearly 6 billion people, but each and every one of us is different from everybody else.

Only you have your combination of looks, personality, and behavior. As the saying goes, they broke the mold when you were made! There is *no one* in the world exactly like you.

At the same time, you have **traits**, or ways of looking, thinking, and being, that you share with some other people on earth. For example, you may look like your father or share your mother's sense of humor.

You also have traits that you share with *every* other person on earth. For example, every person has blood, lungs, and a brain. All things considered, you are more like every other person on earth than you are different from them.



One way that scientists know this to be true is by studying our **genes**. Genes are units of information inside the cells of your body. They contain the instructions for making cells and for doing the work that goes on inside them. It is through the genes that traits are handed down from parents to offspring, in a process called **heredity**. Genes help decide your size, build, coloring, and other features. They make you male or female. Researchers believe that genes also play a part in how you think and behave and in your body's health.

The human body is very complicated, so it makes sense that it needs a lot of instructions. Scientists don't yet know the exact number of genes that humans have, but they think that the number is somewhere around 80,000. Inside each one of those genes are distinct chemical ingredients called **bases**. The bases are linked together in long chains, with thousands or millions of bases per gene. Millions more bases link the genes together. Add up all these small parts, and you have 3 billion separate pieces that make up the human instruction book. Yet of these 3 billion pieces, only about 3 million are different from person to person. These are the parts that make you unique.

Now, 3 million is a huge number, but it is not much compared to 3 billion. What this means is that all human beings are built from nearly the same set of instructions. We are all really quite similar.



Genes determine physical traits like eye color.

Genetics

How does a set of instructions work to create humans and other forms of life? This is the subject of a field of science called **genetics**. Genetics is the study of how traits are passed down, or inherited, from one generation to another. It is the study of how each living thing is similar to others of its kind, but also unique.

For hundreds of years, people have known that traits can be inherited. They observed how looks were passed down from parents to children. They noticed how illnesses run in families. They used their understanding of inheritance to breed plants and animals. But no one really understood how this passing down of traits actually worked.

Then, about 400 years ago, the microscope was invented, and for the first time, scientists could see objects as tiny as a cell. They discovered that living things are created from cells of their parents. They also learned that living things grow when their cells divide to form new cells. As more powerful microscopes were invented, scientists could even look inside cells to watch what happened as they divided and reproduced.

Scientists also learned about heredity by studying plants, fruit flies, and other forms of life, or species, that produce several generations in a short period of time. They discovered patterns in the way that traits are passed down in a **species** from one generation to the next. And they learned how species change over time, trait by trait, in a process called **evolution**.

Slowly, scientists began to unravel the mystery of genetics. Today, powerful computers and other modern research tools are helping scientists learn a great deal more, at a much faster pace. They are figuring out how genes work to do what they do. And they are uncovering the functions of specific genes.



These discoveries are teaching us a great deal about the genetic instructions that construct and operate the human body. This new information will give us new opportunities to control the destiny of our bodies. But at the same time, it will force us to face new and sometimes difficult choices. Some of these choices will have to be made by individuals or families. Other choices will be made by all of us together, as a society.

Questions Raised by the “New Genetics”

To get an idea of the many choices that come with the new genetic information, consider Martin, the boy who is albino.

Martin is albino because his genes do not give the right instructions for his body’s production of **pigment**, the dye that colors the skin, eyes, and hair. The result is that Martin is very pale. He must avoid the sun because he is at high risk of sunburn and skin cancer. Strong light hurts his eyes, and his vision is poor, so he needs glasses.

Suppose researchers discover a way to treat Martin’s genes so that they give the proper instructions for producing pigment. This kind of genetic treatment may be possible someday. It would mean that Martin’s skin and eyes would regain color. He no longer would have to stay out of the sun all the time. Plus, he wouldn’t stand out from other children. These changes could make a big difference in Martin’s life.

Do you think Martin should have the genetic treatment? In other words, do you think being albino is a medical problem that needs fixing? Or would you say the treatment is more along the lines of a nose job or face-lift—something nice, but not necessary?

Your answers to these questions are important, because genetic treatment could be expensive. Should health insurance pay for it? Maybe you say yes. However, the cost of this treatment for people who are albino may drive up the cost of health insurance for everyone. Would that change your answer?

Think about the choices Martin’s mother would have to make. If she loves Martin the way he is, how does she explain a decision to have him treated? But if *he* is unhappy with the way he is, how does she explain a decision *not* to treat him? Also, many medical treatments have side effects. What level of risk is acceptable?

Perhaps when Martin grows up, he will decide that he wants to prevent his children from having the problem he has had. He may decide to have any baby of his tested before it is born, to make sure it is not albino. If it is, he and his wife could choose to have an abortion and try again. What do you think of this choice?

Adoption is another choice Martin and his wife could make, instead of risking bearing children who are albino. With adoption, the children would not be their own, genetically. But Martin and his wife could raise the children as their own, and they would not be albino. What do you think of this choice?

It's possible that when Martin grows up, he will be comfortable with how he looks. He may not care whether his children are born albino. In fact, he may even prefer it because then they would look more like him. What do you think about this? Do you think it is wise to let children into the world with problem skin and poor eyesight if we know how to keep this from happening? Another way to ask this is, Should Martin be prevented from having children who are albino? Who are we to say no to him?

A lot of people don't like their skin color. They would rather be darker or lighter. When these people learn about the treatment that can help Martin, they may want it, too. Should they be able to get it? Perhaps you say, "Sure, if they want to pay for it." But what if skin color is something only the wealthy are able to choose?

Finally, there is the question of where society should put its time and money. Perhaps along with research into the treatment of genetic conditions, we should put equal effort into teaching children (and adults) to accept those who are different. What do you think?

These questions are just the "tip of the iceberg" when it comes to genetic research. There are many more. One way to explore the topic is to look at it in terms of the **ethical, legal, and social issues**. Ethical issues concern what is moral or right. Legal issues concern the protections that laws or regulations should provide. And social issues concern how society as a whole (and individuals in society) will be affected by events. To really get into all of these issues, you first need to know some of the basic science of genetics. That comes in our next chapter.



Chapter 2

Priya Should Find Out She Inherited a Fatal Disease (or should she?)

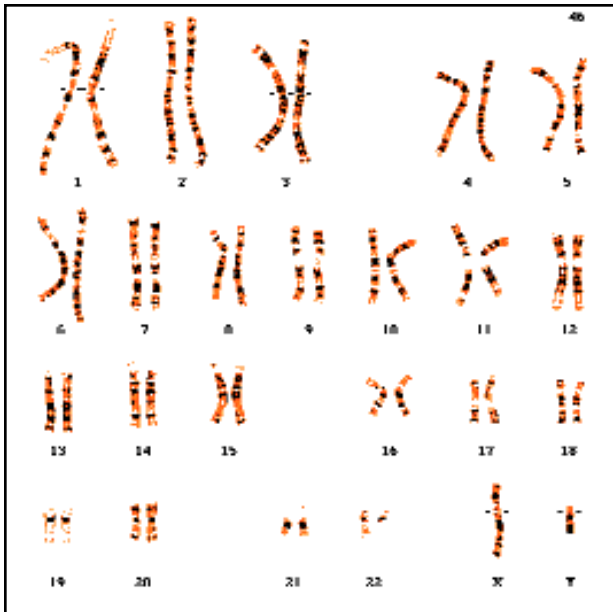
Priya has just lost her mother to an illness called **Huntington's disease**. It was hard for Priya to watch her mother die. First her mother had strange changes of mood. Then her arms and legs began twitching. Soon she couldn't talk or control her movements. In the end, she was totally bedridden and could barely get food down without choking.

Priya knows that Huntington's disease usually strikes people in middle age. It is always fatal, and there is no treatment. She also knows that since the disease is inherited, she has a strong chance of getting it herself.

Priya just learned about a test she can take. The test will tell if she carries the gene for Huntington's disease.

She is tempted to take the test. She thinks that if she could find out once and for all whether she will get the disease, she could plan for her future. On the other hand, she wonders if it is better not knowing. At least then Priya would still have some hope.

If you were Priya, what would you do?



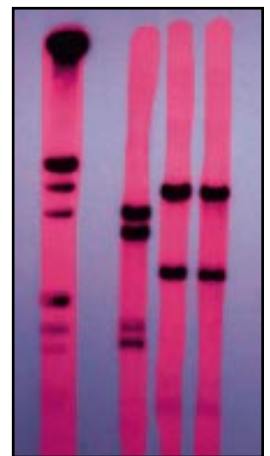
*This photograph shows a person's 23 pairs of **chromosomes**. Each parent contributes one chromosome to each pair. You can tell by the presence of the "Y" chromosome that this person is male.*

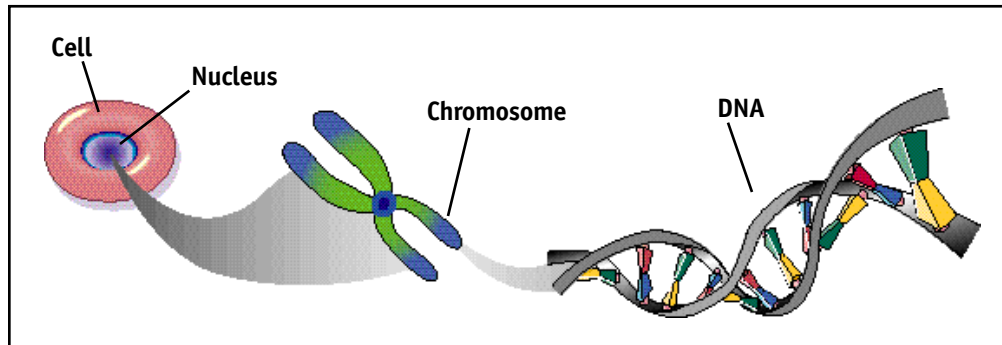
In Chapter 1, we said that genes contain the instructions for making cells and for the work that goes on inside them. The complete set of genes for a human being is called the human **genome**. It may help to think of the human genome as a book of instructions, with each gene a single instruction. You have a copy of this instruction book inside nearly every one of the trillions of cells in your body. The book is written in an unknown language that only your cells can read.

We will have to learn this language if we want to learn all the secrets of the genes. So this is exactly what scientists from around the world have decided to do. They have set out to learn the language of the genes. This international effort is called the **Human Genome Project**. The United States is spending 3 billion dollars over 15 years on this project. Other countries also are investing large amounts on research. It is a huge undertaking that involves researchers in biology, physics, engineering, computer science, and many other fields.

The task they have taken on is challenging and exciting, but difficult. Genes are made of a threadlike material called **DNA**, which itself contains chemical ingredients called bases. There are only four bases, but they repeat one after the other in an ever-changing order throughout the genes. Think of the four bases as letters of the alphabet, combining together in some strange language to spell out each gene's instruction.

Chromosomes are made up of thousands of genes. This is a photograph of an actual gene.

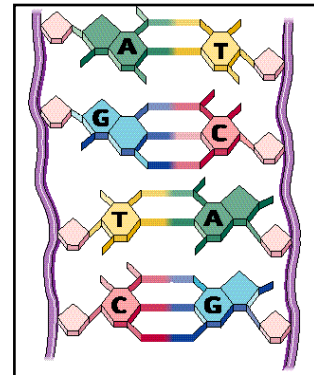
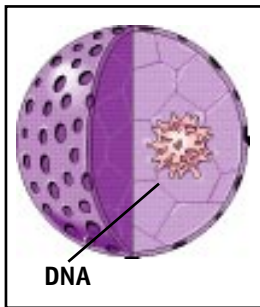
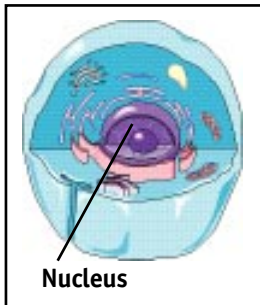




With just four letters, the alphabet of this mysterious language is very short. However, the words written in this language are not short at all. A single gene has thousands of bases. Some genes have millions of bases. So each gene is like a single word with thousands or millions of letters to it. In addition, it is hard to figure out where each gene begins and ends, because the spaces in between also are filled with long strings of letters.

The immediate goal of the Human Genome Project is to put together a copy of the human instruction book, letter by letter. Having this copy to read will make it easier to decipher the language of the genes. But making the copy is very difficult. First, scientists have to get inside a cell. Then they have to get inside the **nucleus** of the cell to the DNA. The DNA is curled into tight coils, so they have to uncurl it. Then they have to look at the DNA to see which of the four bases comes first, which second, which third, and so on. Then they have to write this down.

It may sound simple, but it isn't. This is a job that involves unthinkably small objects and incredibly large numbers. It would seem to be an impossible task. Yet, because of advances in computers, microscopes, chemical analysis, and other tools of science, it is a job that is only a few years from being done.



Your Unique Genome

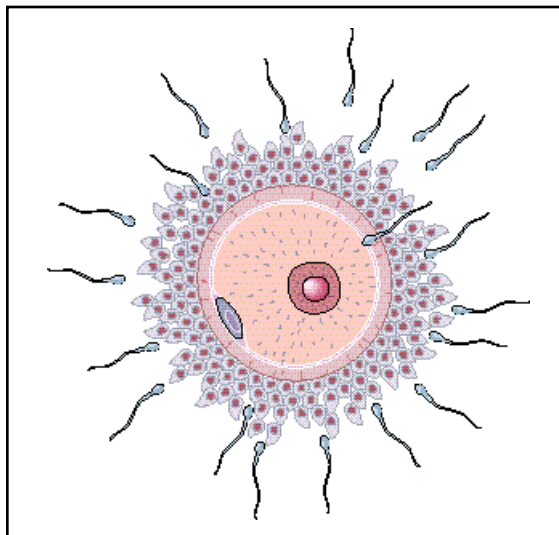
Once the Human Genome Project has made its copy of the human instruction book, there will still be the task of translating what it means.

And even when this translation has been done, it will only be a model. It will not reveal exactly what is written in your genome or in any other particular person's genome. This is because every human being is different. Each person's genome is unique.

Your unique genome was given to you by your parents. This took place in the process of **conception**. Conception is when a man's sperm fertilizes a woman's egg.

Sperm and eggs are made from special cells called germ cells. (The word "germ" is from the Latin word for "seed" or "bud".) Germ cells are found in the male's testes and in the female's ovaries. Like most other cells, each germ cell has a copy of the genome inside it. The genome is not one long strand of DNA. Rather, it is divided into separate strands called **chromosomes**, each containing several thousand genes. Human beings have 46 chromosomes.

To make sperm (in a man) or eggs (in a woman), a germ cell goes through a complicated process. First, it makes a copy of each chromosome. Then it divides, twice, to form four sperm or four eggs. Its double set of chromosomes is sorted equally among the four sperm or eggs, so that each has a half set of 23.



When a sperm and an egg join together, they combine their half sets to make a unique, new set of 46 chromosomes. There are so many different ways that your parents' chromosomes can be combined, that the chance of the same mix happening twice is close to zero.

The chance becomes truly zero because of something that happens as sperm and egg are formed. That something is called **crossing over**. It happens when a germ cell is making copies of its chromosomes before dividing. In crossing over, a section of one chromosome switches places with the same section from its pair. This makes the copied chromosome a little different from the original. It will carry a slightly different mix of genes.

Along with the random mixing of chromosomes, crossing over contributes to uniqueness. This is what makes you one of a kind.

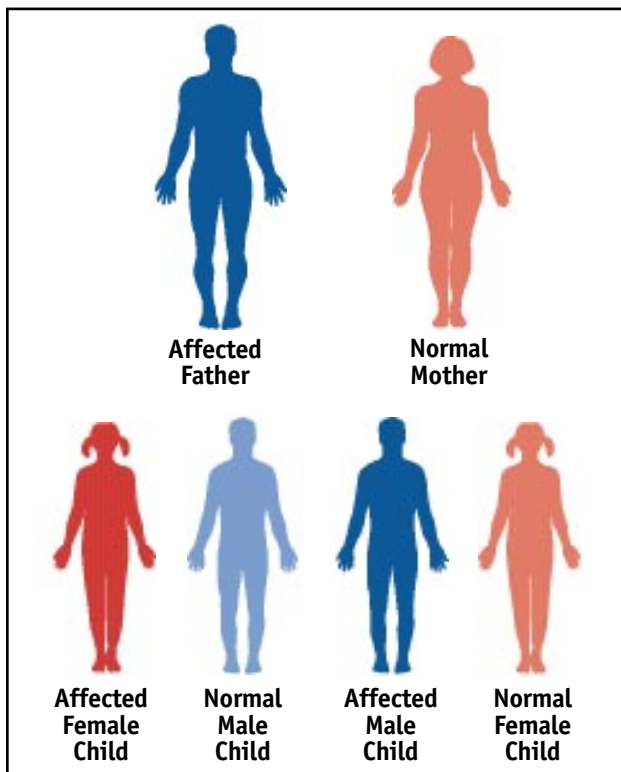
Dominant and Recessive Genes

The chromosomes you inherit from each parent correspond in size and in the genes they carry. The one exception to this rule involves the two chromosomes that determine sex, nicknamed X and Y. A person who inherits two X chromosomes (XX) is female, while a person who inherits one X and one Y chromosome (XY) is male. The X chromosome is larger and contains genes that are not found on its partner Y chromosome.

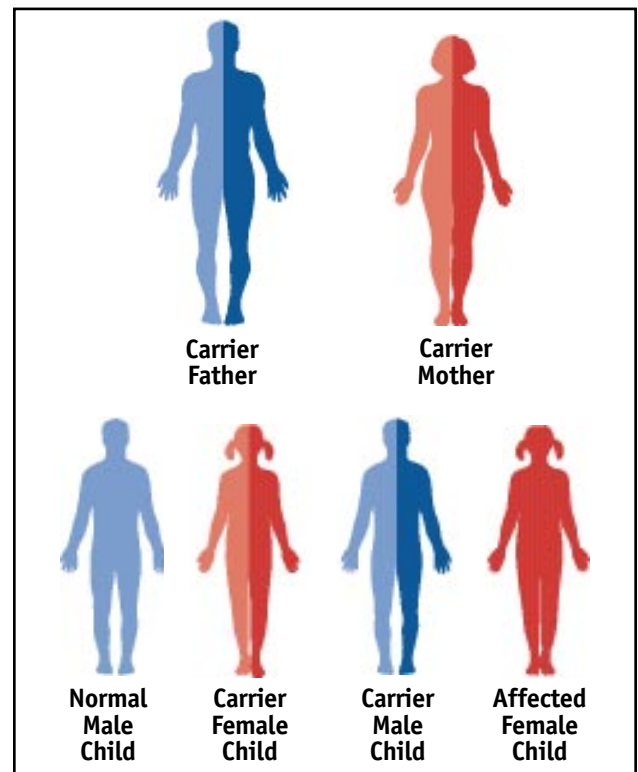
The fact that you have pairs of chromosomes means that you have pairs of genes for every trait (except for those traits found only on the X chromosome). So which instruction in each pair gets followed? It depends on whether the genes in the pair are **dominant** or **recessive**. In any pair, if one gene is dominant over the other, its instructions are followed. A recessive gene's instructions come into play only if neither gene in its pair is dominant.

For example, the gene for Type A blood is dominant over the gene for Type O blood. Therefore, if you inherit the Type A gene from one parent and the Type O gene from your other parent, you will have Type A blood. The gene for Type B also is dominant over the gene for Type O. So if you inherit one Type B gene and one Type O gene, you will have Type B blood. Because the Type O gene is recessive, you will have Type O blood only if you inherit two Type O genes, one from each parent.

Something very interesting happens, however, if you inherit one Type A gene and one Type B gene. In this case, you will have Type AB blood. The instructions of both genes come into play because neither dominates over the other. In fact, many of your traits are shaped by both genes in a pair. In addition, most traits are affected by more than one gene. For example, the shade of your hair is affected by many pairs of genes working together.



In dominant genetic disorders, if one affected parent has a disease-causing gene that dominates its normal counterpart, each child in the family has a 50% chance of inheriting the disease causing gene and the disorder.



In diseases associated with altered recessive genes, both parents—although disease free themselves—carry one normal gene and one altered gene. Each child has one chance in four of inheriting two altered genes and developing the disorder, one chance in four of inheriting two normal genes, and two chances in four of inheriting one normal and one altered gene and being a carrier like both of the parents.

How Genes Instruct Your Body

When a gene becomes active, it leads to the production of a **protein**. Proteins are the basic chemicals that make up the structure of cells and direct their activities. The human body produces thousands of different proteins. Most every protein has a different function, although there is some overlapping of jobs.

For example, one protein carries oxygen in the blood. Another protein regulates the salt in your sweat. For every function of your body, proteins are involved, and the production of these proteins is regulated by genes.

A gene in one person may carry a slightly different instruction than the corresponding gene in another person. Most variations in the same gene don't cause any problems to health. For example, a person whose genes lead to blue eyes can see just as well as a person whose genes lead to brown eyes.

Mutations

Variations in the instruction carried by a gene come about through a process called **mutation**. A mutation is a change that occurs to the order of the bases appearing in the DNA inside a cell. Mutations can happen to any gene inside any cell of your body at any point in your life. However, most mutations occur as germ cells make copies of their chromosomes before dividing to form sperm or eggs. In this process, millions of bases must be copied in exactly the right order. Mostly, they are. However, with every copy of DNA, there are some errors. A base is put in the wrong place or is left out. Sometimes extra copies are made of a string of bases or of whole chromosomes.

These kind of changes can alter the order of bases in the affected genes. Therefore, the instructions that direct the production of proteins may change. This can affect the traits that show up.

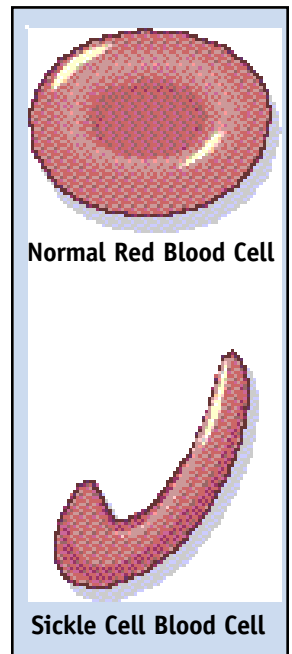
Many mutations happened to the genes of people who lived long ago, and these mutations have been passed down through the generations. Others are new, occurring to a person during his or her lifetime. New mutations may be passed on to the next generation if they appear in sperm or egg cells.

Inherited mutations are carried in the DNA of reproductive cells. When reproductive cells containing mutations combine to produce offspring, the mutation will be present in all body cells of the offspring.

Most mutations are harmless because they don't result in any important changes to traits. Some mutations are important because the new trait is helpful to the survival of a species. However, sometimes mutations cause problems in how your body functions. These problems are called **disorders**.

An interesting example of a mutation is the one that causes red blood cells to take on an unusual "sickle" shape, like the curving blade of a knife called a sickle that is used to cut tall grasses. This gene variation is found mainly in people who live near the equator (or whose ancestors did). Researchers believe that inheriting *one* gene with this particular variation may be helpful against malaria, which is a disease caused by **parasites** transmitted by mosquitoes into the bloodstream. The parasites feed off red blood cells. However, they have a hard time feeding off sickle-shaped cells. This limits the damage they can do inside the body.

People who inherit *two* copies of this gene variation, however, are affected by a disorder called **sickle cell anemia**. They have so many sickle-shaped red blood cells that sometimes it is hard for the blood to flow. The symptoms for sickle cell anemia range from mild to severe. Although treatment has improved in the past few decades, many people still become very sick and die from the disease.

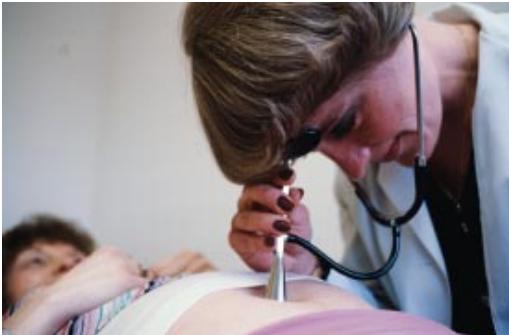


Genetic Testing

In the past few years, researchers have learned how to test for hundreds of genetic disorders. More new tests are coming out all the time. These tests can be very helpful for diagnosing disorders in children and adults. The tests also can be used to predict the chances that a person will come down with a particular disease later in life.

Genetic tests are sometimes used by couples who want to learn their risk of passing on genetic disorders to any children they might have. Other genetic tests are **prenatal**. That is, the tests are done before birth to an **embryo** or **fetus**, to see whether it has any genetic problems.

There are many different kinds of tests. The test used depends on what disorder is being looked for and what is known about the gene, such as its location in the genome or the protein it controls. In some cases, the test results are definite. In other cases, the test results only suggest what the person's *risk* is for developing a disorder.



Doctors can perform many tests before birth to check for abnormalities.

One way of testing is to do a medical exam. Doctors examine the person to see if he or she shows signs of the disorder. They also may study the person's family history for clues as to how the disorder has been passed down from generation to generation.

To find some disorders, doctors may take a blood sample in order to look at the person's chromosomes under a microscope. They may test the blood sample to find proteins that would reveal a gene at work. Very advanced tests can look inside a section of a chromosome to "read" the DNA.

Concerns About Genetic Testing

Great progress has been made in genetic testing in recent years. However, progress in the treatment of genetic disorders has been much slower. That is the problem for Priya, the woman who fears that she may have inherited Huntington's disease (HD).

HD affects 1 in every 10,000 people. A mutation in one gene means that the protein it instructs the body to make gets produced abnormally. For reasons that are not yet clear, this leads to a breakdown in the parts of the brain that control movement.

The HD gene is dominant. This means that only one gene in a corresponding pair needs to carry the HD mutation in order for the disease to take hold. Priya's mother had the gene and, therefore, the disease. If Priya inherited the HD gene from her mother, she too will someday develop the disease. This will be true even if the corresponding gene she inherited from her father does not have the HD mutation.

Genetic tests are available to tell Priya if she carries the gene for the disorder. However, no treatment is available. If Priya finds out through testing that she has the gene, there is little she can do. No one knows how to ward off the disease or keep it from getting worse. No one can even tell when the disease will hit or how quickly it will take over her body.

In other words, the only real use of the test is to tell Priya how she stands, one way or the other. Such news could change her life, but not necessarily in the way she expects.

For example, you might think that Priya would be happy to find out from testing that she has been spared the disease. However, it is possible that she will feel “survivor’s guilt” if other members of her family have not been spared. It also is possible that once Priya stops worrying about HD, she may discover other problems in her life that she has been avoiding. Finding out that she doesn’t have HD may be happy news, but it will not necessarily make Priya a happy person.

You might also think that Priya would be sad to find out from testing that she will get the disease. But Priya may discover that it is a big relief to know for sure what she has always feared. It may give her a new appreciation for each day that she has. She may feel that she can now make better decisions for the life she has left.

The fact is, Priya cannot know ahead of time how she will react to the test results. And she cannot predict other problems that may come as a result of testing. For example, in order to find out how HD is passed down in her family, doctors may want to test her close relatives, such as her brothers, sisters, aunts, and uncles. This is called a **genetic linkage** study. Priya will have to ask them to take part in the study. Asking such a thing can be very difficult. It may put extra pressure on her when she already has a lot on her mind. The relatives may feel pressured themselves. Or they may feel guilty if they refuse to take part.

Here’s another problem Priya must consider: Suppose the test result says that she has the HD gene. Who else should know? Does her boyfriend have a right to know before they make plans to marry and have children? When does she tell her employer, now or when she becomes ill? What about her health insurance company, which at some point may have to provide expensive medical care for Priya?



Priya must decide how to handle the information in a way that is fair to herself and to others. However, it may not be entirely in her control. She may want to keep it secret, but have a hard time doing so. Or a relative who took part in the testing may reveal information to others. If information on the results of the test is put into her medical records, both her employer and her health insurance company may find out without her telling them. This could cause her to lose her job, which would be illegal, but still could happen. Or it could cause her to lose her health insurance, which has indeed happened to others in this situation.

Another thing that Priya must think about is that testing could take a lot of time and be expensive. She could have a long, distressing wait for results. The answer may not be clear cut. It is even possible that the answer will be wrong because of a lab error or because the test itself is not perfect.

Priya's decision whether to get tested may be affected by recent news. In 1993, researchers located the gene in which the HD mutation occurs. This discovery means that scientists can develop a simpler and more reliable way to test for HD. The information also is useful for scientists working on a cure. Treatment may come in time to help someone like Priya. Then again, it may not.

The Need for Genetic Counseling

HD is unusual because if you carry the gene for the disorder, you get the disease for sure and it kills for sure. Most genetic disorders are not so direct. But the issues surrounding testing remain.

That's why many people feel that **genetic counseling** is extremely important for anyone wanting to get information about their genes. With counseling from professional advisors who are experts on genetics, people like Priya can understand the facts of their situation. Counselors can help them clearly understand the limitations of tests and think through ahead of time how different test results might affect them. Finally, counselors can explain to people what their choices are once they know the results.

However, genetic counseling is a new field, and there aren't very many trained genetic counselors. Genetic testing is fast becoming a billion-dollar industry. New tests are coming out faster than new counselors are being trained. There simply aren't enough genetic counselors for everyone who should have counseling.

This problem is probably going to get worse before it gets better. Companies that sell tests want to make a profit, so they will be marketing them not just to genetics specialists, but to all doctors and directly to the public. As people hear about new tests, demand for them will surely increase. This is especially likely to happen as the tests become cheaper, more accurate, and easier to perform. People getting tested may not realize that they need to have the results explained to them. They may not know how to ask for this. Also, doctors who perform the genetic tests, but who do not have special training in ,may not be able to answer their patients' questions.



Some people who have genetic tests may not get counseling even if they want it, because their insurance company will pay for testing, but not for the counseling to go with it. All of this means that a lot of people may be getting very serious information from tests without getting the support they need to understand the results and to make good decisions.

There's one more reason why genetic counseling is so important. With many genetic disorders, genes are only one of the factors involved. Other factors, such as lifestyle, play a part. Counselors can help people understand what they can do to avoid triggering a genetic disorder. These kinds of choices are covered in our next chapter.



Chapter 3

Howard's Health Is Up to Him (or is it?)

Howard will turn 50 soon, and it worries him. His grandfather died of a heart attack in his fifties, and so did his father and uncle.

Several years ago, a doctor told Howard that he was at high risk for heart disease because of his family history. But the doctor said that Howard could improve his chances if he lost some weight, stopped smoking, and exercised. The doctor also told Howard to come back every year for a checkup.

Howard hasn't gone on a diet, and he hasn't given up his cigarettes or taken up exercise. He also hasn't been back to the doctor. He's afraid of what the doctor might find.

Howard can't make up his mind. Sometimes he thinks he should try to take better care of his health. Other times, he thinks that he should just accept the fact that he won't live much longer and should get as much fun out of life while he can.

If you were Howard, what would you do?

Researchers now believe that some of the roots of cancer, high blood pressure, and perhaps even alcoholism are found in the genes. They also believe that genes may play a role in the development of certain cases of obesity, some types of depression, and diabetes. The more they search, the more they are finding a link between genes and disease.

However, the truth is always complicated. It isn't so simple as "if you have the gene for a disease, you will get the disease." Here are some of the reasons why:

- ▼ *While genes play a role in many disorders, so do the conditions and circumstances of your life and the decisions you make.* In other words, heredity may influence your health, but so does your **environment**. For example, some people have genes that put them at risk for cancer. However, their chance of actually getting cancer may be much less if they do not smoke. Some people have genes that put them at risk for diabetes. But, they may never become diabetic if they watch their weight.

Some people have genes that put them at risk for asthma. Still, they may only begin to wheeze and cough when cats are nearby. Diet, exercise, levels of stress, and access to health care are just a few of the many environmental factors that can influence the course of a gene-related disorder. Some factors in your environment are under your control, and some are not. Either way, they can affect the progress of gene-related disorders.

- ▼ *Only a few human diseases are triggered by a single gene working by itself. In most cases, a disease results from the actions of many genes.* An example of a single-gene disorder is Huntington's disease, which was discussed in the last chapter. One error in one gene leads to the fatal health problems of HD. Multiple-gene disorders, where several mutated genes come into play to trigger the problem, are much more common. Examples of multiple-gene disorders include breast cancer, asthma, and diabetes.
- ▼ *The "strength" of the genes involved in a disorder can affect its progress.* Scientists call this **genetic expression**. Take two people who have the same disease-causing gene and have pretty much the same lifestyle. In one of those persons, the gene "expresses itself" mildly. The failures in its instruction for producing a protein are rather minor. Enough of the protein is produced so that the body can stay healthy for a long time. The disease moves slowly if and when it appears. In the other person, the gene "expresses itself" strongly. The failures in its instruction for making a protein are major. A necessary protein does not get produced or is produced in the wrong amounts. The body cannot stay healthy. That person becomes ill at an early age or comes down with a severe case of the illness.

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- ▼ *In many cases, different mutations in different genes can lead to the same basic problem.* An example of this is the albino condition that affected Martin, discussed in Chapter 1. The lack of skin, eye, and hair color can be caused by mutations in several different genes that are involved in the making of pigment. In some cases, the mutations result in patches of colorless skin or hair. With other mutations, the entire body has no pigment. Often, a person who has genes that cause albino coloring also has mutations in other genes that lead to mental retardation and growth problems. In each case, the disorder is called “albinism.” However, the genes involved are different, and the result is slightly different, too.
 - ▼ *While there are many diseases that involve mutated genes, the reverse is not true. Many mutated genes do not lead to disease.* Sometimes people have what look like “problem” genes because they are different from those of many other people. However, these unusual gene variations don’t necessarily lead to disease.
 - ▼ *Some people carry a gene mutation that causes a disorder, but are not at risk for the disorder themselves.* This happens when the gene mutation is recessive. You need to inherit two such mutated genes (one from each parent) for the disease to be triggered. If you inherit only one, you won’t get sick. You will, however, be a **carrier** to the next generation. This means that you may pass on the mutated gene to your children without ever showing any symptoms yourself. Your children will be at risk for getting the disease only if they inherit the disease-causing gene mutation from both you and their other parent. An example of a recessive disorder is sickle cell anemia, which was discussed in the last chapter.
 - ▼ *Some disorders occur when healthy genes become damaged.* Gene damage can be caused by exposure to radiation or by a viral infection. It also can happen if you come into contact with cancer-causing substances, called **carcinogens**. Aging also introduces errors into the DNA. Depending on which genes have been damaged, and how many, different disorders may be triggered. Some people’s genes appear to be more easily damaged than others. Such people are at higher risk for disorders caused by damage to healthy genes.

The truth is that everyone has at least a handful of “problem” genes. Your genes may never cause you trouble...

...*if* factors in your environment do not “trigger” the genes for a disorder...

...*if* you only have some, but not all, of the genes that come into play to cause a particular disease...

...*if* your genes for disorders don’t express themselves strongly...

...*if* you have genes that only lead to a mild form of a disease or disorder...

...*if* your unusual genes have no effect on health...

...*if* your genes for disorders are recessive and you inherit only one copy, and...

...*if* your genes are not damaged by substances in the environment or by aging.

Genetic Determinism

Research tells us that there is no simple link between genes and disorders. Genes have *something*, but not *everything*, to do with disorders. Genes do not equal fate.

However, it is easy to fall into that simple way of thinking. The misunderstanding that genes by themselves can determine what happens to you is called **genetic determinism**. Genetic determinism can lead people to make harmful and unfair judgments about themselves and others.

This kind of simple thinking is leading Howard to fear that, no matter what he does, he will die of a heart attack just like his father, uncle and grandfather. The fact that three of Howard’s close relatives died of heart attacks strongly suggests that Howard himself is at risk. He may have inherited genes that make his body less able to resist heart disease.

Researchers don't yet know how many genes are involved in heart disease or how they work to bring about the illness. There is no test yet that can tell Howard whether he has any or all of the genes that can lead to a heart attack.

However, researchers do know something about the kinds of behavior that can trigger heart disease. They know that it occurs more often in people who smoke, have high blood pressure, eat high-fat diets, and do not exercise.

So maybe the reason that Howard's relatives died of heart attacks is that they smoked, worried a lot, ate fatty foods all the time, and sat around too much. Maybe Howard *can* improve his chances by taking better care of himself.

On the other hand, it is possible that Howard's family carries heart disease genes that express themselves very strongly. It is possible that no matter what Howard does to keep fit, he *can't* stop those genes from bringing on a heart attack.

The fact remains that Howard simply does not know what his risks are. The way that genes and other factors work together to produce heart disease is so complicated that doctors may never be able to make any safe predictions.

Of course, Howard also needs to remember that his cause of death could have nothing to do with genes. A car accident or a bolt of lightning could get him tomorrow. No matter how much Howard learns about his genes, he will never be able to read his future.

Dealing with Genetic Knowledge

Like Howard, we all must make decisions about the way we live our lives. More and more, however, our decisions will be influenced by information we have about our genes.

Not too far in the future could be a single test that will examine thousands of your genes. The test will reveal whether any of these genes are unusual or defective.

Knowing your **genetic profile** could be very helpful to you. It could suggest what health-related behaviors you should follow. It could tip you off to have frequent checkups for genetic conditions for which you are at risk. It could help you plan your life so that you avoid behaviors and substances that trigger diseases.

At the same time, knowing your genetic profile could create problems for you. As we said earlier, everyone has a number of “problem” genes. For the most part, you don’t know what your problem genes are, and you never will find out unless a health problem surfaces. A piece of paper that lists these “problem” genes could give you a lot of things to worry about that may never come to pass.

It is possible that people who learn their genetic profile will limit the choices they make based on such fears. People may choose not to marry or build a career because they believe that they are doomed by their “problem” genes. The expectation of disease may ruin their enjoyment of life.

A big question is whether children should be told information about the genes they carry or, if so, at what age they should be told. It can be difficult for children to understand some of the important facts about genetics, such as the difference between a risk and a sure thing. There is the possibility that they will misunderstand what they are told.

There also is the risk that they will not be mature enough to cope with the information. For example, if a girl has the gene that puts her at high risk for breast cancer when she is in her forties, should she be told? It may seem that the best thing is to avoid getting this information. However, many parents want to know if their children are at risk for genetic disorders. That way, the parents can be prepared and get treatment for the children in time. They also could make lifestyle choices to avoid triggering the disorder in their child. Parents will have to decide whether and how to share genetic information with their children. Society also may have some say in how genetic information is shared with children, through standards, laws, and regulations that are developed.



Discrimination Based on Genes



For some people, information about their “problem” genes can bring extra trouble. For example, it can cost them their health insurance. People with “problem” genes have been refused health insurance or dropped from their health plans. In other cases, they have been told that medical expenses for their genetic condition will not be covered. In still others, they have been told that their children will not be covered because they are at risk for inheriting genetic diseases. The number of such cases may increase as genetic testing becomes more common.

You might think that it makes sense to keep genetic information about you to yourself. But this may not be possible. Part of your genetic profile may be obvious to others from your family’s medical history. Also, the results of genetic tests usually go into your medical records. Insurance companies may demand to see these records before they will cover you.

Some people are concerned that employers may try to use genetic information to weed out workers who are sick, or who may someday become sick, because of a genetic disorder. Under the 1990 [Americans with Disabilities Act \(ADA\)](#), it is against the law to discriminate against workers who are disabled. The federal Equal Employment Opportunity Commission has ruled that the ADA also protects people from discrimination based on their genetic profile.

However, the fear of being discriminated against may lead people to refuse genetic testing even when it could help diagnose, prevent or treat a health problem. They may be too afraid that the information will be used against them. If that happens, then all the benefits of genetic research could come to nothing.

Genes and Behavior

In Howard's case, it didn't take any special genetic test to reveal that he is at risk for a heart attack. His risk is clear from his family's medical history and from his own smoking, eating, and exercise habits. Given these facts, Howard has a choice: whether or not to reduce his risk by adopting a healthier lifestyle.

But this raises an interesting question: How much control does Howard have over the choices he makes? If Howard decides to change his ways, is that because his genes have made him a careful person? If Howard rejects his doctor's advice, is that because his genes have made him reckless?

The study of whether and how traits for behavior are inherited is called **behavioral genetics**. Scientists have long tried to figure out whether behavior is shaped by our genes or by how we are raised. It is called the question of "nature versus nurture." For a long time, scientists took one position or the other. They believed that either nature or nurture was responsible, but not both. Today, most scientists agree that both genes (nature) and environment (nurture) help make us who we are. What no one knows is just how nature and nurture work together.

Some researchers believe that genes shape our inborn frame of mind, or **temperament**. According to this theory, we may inherit our tendency to be shy or bold, risk-taking or cautious. However, any temperament we inherit is shaped and altered by our experiences from the moment we are born. For example, a shy boy who is encouraged to try out new situations may learn to be more outgoing. Another shy child who is pushed too quickly into strange situations may always remain timid. So might a shy child who is allowed to hide behind his parents.

There is some evidence that to some degree, abilities also may be inherited. But any such genetic trait is heavily shaped by experience. A girl who is never allowed to play sports may never develop her inborn athletic talent. The reverse also is true. A girl whose genes do not give her any athletic advantage may still become a star if she is encouraged to play, practices hard, and keeps at it.

Many people are interested in how genes shape other personal characteristics, such as sexual orientation, intelligence, and social behavior. Research into these areas is very controversial and raises many questions. For example, some researchers are trying to find out if there are any genes that contribute to homosexuality. But what if there are, and what if there aren't? If homosexual identity is caused in part by the genes, does this mean that society should be more accepting of it? On the other hand, should society be more accepting of homosexual behavior even if it is purely a lifestyle choice?



Other researchers are trying to determine how genes shape intelligence. The question is, what do we do with this information? If intelligence is controlled in part by the genes, should society spend more money educating those who lack genetic smarts to give them a boost? Or should it spend more money on the genetically gifted, who could make more use of the education? And take the question of a genetic link to criminal behavior. If such a link is found, should the police keep close tabs on people with “criminal” genes? Should such people be excused for crimes they commit, since their genes are at fault?

Some people are critical of theories linking genes and certain kinds of behavior. They say that these theories are often based on fanciful thinking or prejudice, not science. They say that this kind of research is easily twisted to support discrimination against minorities. In any event, research suggests that environment is at least as powerful a shaper of behavior as genes. And there is still the role of personal responsibility. Shy or bold, risk-taking or cautious, it is still within Howard's power to choose whether to quit smoking, to give up sweets, and to start jogging. Most researchers do *not* believe that our genes fully explain our behavior.

As you can see, genetic research doesn't give us all the answers. But it surely does open up some interesting questions. This is particularly true for the part of health care that has to do with making babies. That's the subject of our next chapter.

Chapter 4

Carlos and Mollie Can Have a Perfectly Healthy Baby (or can they?)



Carlos and Mollie want to have children. However, they haven't tried to start a family yet because they disagree on something important. Carlos wants Mollie to get tested to see if she is a carrier for **cystic fibrosis (CF)**. Mollie doesn't want to do it.

People with CF have mutations in one or more genes. These mutated genes give faulty instructions for the production of proteins that help move salt in the body. One result is that the lungs become clogged with mucus, making it hard to breathe. Another result is that the body has a hard time digesting food. The disease can be painful and lead to an early death.

Carlos had a brother with CF. He hated seeing his brother suffer so much. His parents struggled with the hardship and expense of caring for a sick child who never made it to adulthood. Carlos doesn't want to repeat that experience in his own life. That's why he had himself tested for CF. Unfortunately, he found out that he is a carrier.

CF is a **recessive disorder**. That means his children will have the disease only if they inherit the mutated gene from both parents. Mollie can get tested to see if she carries the CF mutation. If she does, then when she gets pregnant they can have the fetus tested to make sure it does not have two CF genes and is therefore free of the disease.

Mollie would prefer simply not knowing what the risks are. She figures that once a baby is in their arms, they will be glad they had it, no matter what.

If you were Mollie or Carlos, what would you do?

“It’s a boy!” or “It’s a girl!”

This surprised and happy cry used to greet the birth of every child. No longer. Many parents already know the sex of their child before it is born, through prenatal testing.

For most parents, learning the sex is just a bonus piece of information. The main reason they had the testing done was to learn whether the fetus had any genetic problems. Prenatal testing is most often done when there is a risk for a disorder. These risks include:

- ▼ *A family history of a genetic disorder.* Any baby could end up with a genetic disorder caused by a new mutation. However, babies who have a disorder in their family tree face an extra risk of inheriting that disorder.
- ▼ *The age of the mother.* For reasons that are not yet clear, older women are more likely to have children with damaged genes.
- ▼ *Problems with earlier pregnancies.* Doctors may recommend prenatal testing for a pregnant woman who already gave birth to a child with genetic defects, has miscarried several times, or has given birth to a stillborn child for unknown reasons. Testing may be able to reveal what the problem is, so that doctors know what to do to help the woman carry a pregnancy to term.

In the near future, prenatal tests may be able to check for an even wider range of genetic disorders. They probably will become more accurate and easier and cheaper to perform. For these reasons, genetic testing during the early stages of pregnancy is likely to become even more widely used than it is today.

Types of Prenatal Tests

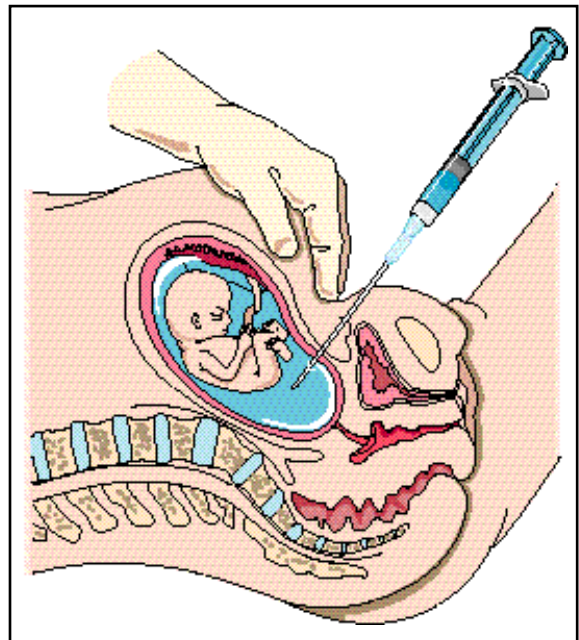
One type of prenatal test commonly used today is the **alpha-fetoprotein test (AFP)**. A sample of the mother’s blood is taken to measure the amount of a special protein produced by the fetus. Too much or too little of the protein indicates that the genes may not be working right. Therefore, the brain or spine of the fetus may not be developing properly. In such cases, other prenatal tests can be done to confirm any problem.

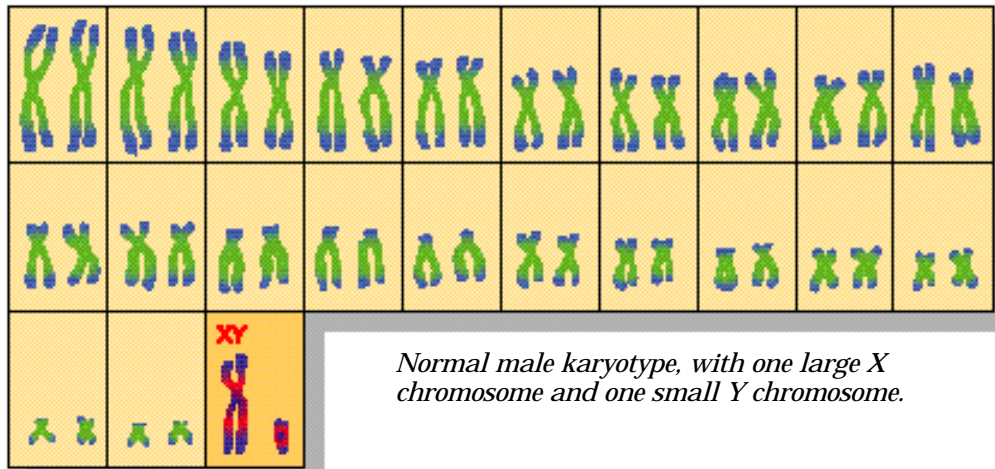
Other prenatal tests check fetal cells to see if important **enzymes** are present. Enzymes are proteins that trigger activity in the cells of the body. Some diseases are caused when the gene that gives the instructions for producing an enzyme doesn't work. When that happens, the enzyme is not produced, and an important function of the body does not occur. This leads to the disease. A particular enzyme test is usually done only when the fetus is at risk for the related disease, for example, if the disease runs in the family.

Another common prenatal test is **ultrasound imaging**. Ultrasound uses sound waves to create an image of the baby inside the mother. Many physical problems can be detected with ultrasound. If something does not look right, the doctor may recommend more tests.

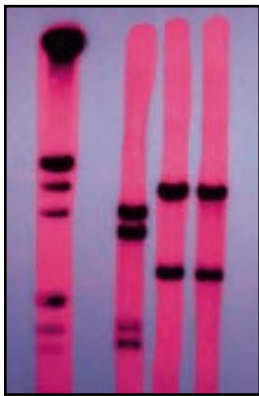
Amniocentesis (called "amnio" for short) and **chorionic villus sampling (CVS)** are tests that check for defects in the chromosomes. Doctors remove some cells surrounding the fetus. These cells are treated with a special dye and photographed through a microscope. In the photograph, the chromosomes will look striped, because of the dye. Corresponding chromosomes will have the same pattern of stripes and be the same size and shape. (There is one exception: the pair of sex chromosomes that men inherit, X and Y, will not match.) A special technique is used to rearrange the chromosomes into pairs. The picture that is created is called a **karyotype**. The karyotype makes it easy to see if any chromosomes are missing or broken, or if there are any extra chromosomes.

Amnio and CVS are also used to obtain cells for analysis at the DNA level. If there is a risk that the fetus will inherit a particular genetic disorder, the gene involved can be looked at to see if it is a disease-causing variation. If the location of the gene is not known, the DNA can be searched for the presence of a **DNA marker**. This is a gene or other fragment of DNA whose location is known and that often is inherited along with the disorder.

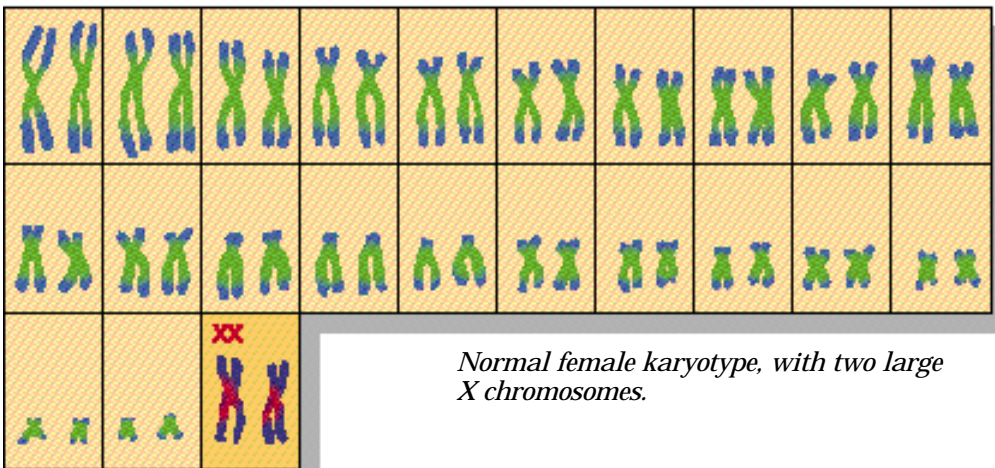




Normal male karyotype, with one large X chromosome and one small Y chromosome.



DNA markers can be seen as black bands when properly stained and viewed under an electron microscope.



Normal female karyotype, with two large X chromosomes.

Reproductive Technology

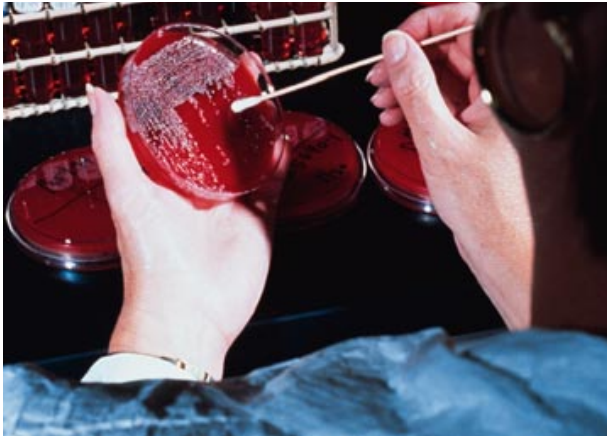
Advances in prenatal testing have come hand in hand with advances in medically assisted ways of making babies. The term for this kind of help is **reproductive technology**. Reproductive technology is often used to help people who have problems conceiving children. It also is used to help people reduce their risk of having babies with genetic disorders.

One form of reproductive technology is **artificial insemination**. This is where a sample of sperm is taken from a man, cleaned in a special way, and then injected into his partner's uterus. If the male in a couple carries a mutated gene causing a **dominant** disorder, the couple may choose artificial insemination using sperm given by a donor. The couple might also make this choice if they both carry the same mutated gene for a **recessive** disorder. In such a case, they would use a donor who does not carry a problem version of the gene. This would protect the child from inheriting the recessive disorder.

Another form of assisted baby-making is called **in vitro fertilization**. A common term for this has been "test tube babies." (*In vitro* means "in glass.") Actually, no test tubes are used. What happens is that a minor operation is performed on a woman to remove some of her eggs. These are mixed with sperm from her partner. Eggs that become fertilized are then implanted in the woman's uterus, with the hope that one or more will grow into a fetus. *In vitro* fertilization with donated eggs is sometimes used when the female of a couple carries a gene mutation that causes a dominant disorder or when she carries a gene mutation for a recessive disorder that her partner also carries.



Artificial insemination involves injecting a man's sperm into a woman's uterus.



Ex utero genetic testing is yet another new technology used in reproduction. (*Ex utero* means “outside the uterus.”) The testing is done after eggs and sperm have been mixed together using *in vitro* fertilization. For any eggs that become fertilized, cells are removed for DNA analysis to see if gene variations that lead to disorders are present. Embryos that do not carry problem versions of the genes are then implanted in the mother’s uterus.

Using reproductive technology may not be a very romantic way to have children. However, combined with prenatal testing, reproductive technology has spared thousands of couples the tragedy of giving birth to a baby with a terrible genetic disorder.

More Decisions to Make

Prenatal testing and reproductive technology are giving more people the opportunity to be parents of healthy children. However, along with these opportunities come decisions that must be made. This is what is creating a problem for Mollie and Carlos, the couple that want to have a baby.

Carlos doesn’t want the baby to inherit CF. CF is a recessive disorder that affects 1 in every 2,500 white babies. (It is much less common in babies of other races.)

Scientists have discovered the gene involved in CF. Many different mutations of this gene lead to CF. A test is available that can identify whether a person has one of the more common mutations linked to the disease. Carlos has taken this test and has been found to carry a CF mutation. Since CF is a recessive disorder, he risks having a child with CF only if Mollie also has a CF mutation. If that is the case, their chance of having a child with the disease is one in four. The risk is the same each time they have a child.

Whether Mollie should get tested or not is just the first decision on a road of choices for this couple. If Mollie refuses, perhaps Carlos will back down from his position, and they will take their chances with a child. Or perhaps Carlos will look for another mate who will agree to take the test. Or perhaps Mollie will look for another mate who is not so afraid of the risk. Then again, perhaps the couple will decide to stay together and not have children, or they may choose to adopt children instead.

If Mollie agrees to be tested, there are two possible results. The test will be positive if she has one of the more common mutations linked to CF. It will be negative if she is not a carrier *or* if she is a carrier for an unusual mutation leading to CF. This means that even with a negative test result, there is a small chance that Mollie and Carlos could still have a child with CF.

If Mollie tests positive, she and Carlos move on to the next choice—whether to have a child together. Here again they may want to consider finding new partners, not having children, or adopting. If they decide to go ahead and conceive together, their next choice is whether to have prenatal testing done on the fetus to see if both of its genes carry a CF mutation. If they have the prenatal test done and it is positive, they face the decision of keeping or aborting the pregnancy.

Their decision will be affected by their beliefs about abortion. It also may be affected by new findings about CF. Modern treatments can keep many people with CF alive into their thirties. Another important new finding is that some people who inherit two CF-mutated genes do not get the full disease. Some only suffer from asthma or lung infections. Some males cannot father children, but have no other health problems. Right now, the genetic test for CF can't always tell how severe the disease will be. If Mollie and Carlos learn through prenatal testing that their fetus has two genes with CF mutations, they still won't know how bad the news is. The baby that is born may become extremely sick or may stay fairly healthy.



Because of this uncertainty, the couple may decide to continue the pregnancy of a fetus that tests say has two genes with CF mutations. In that case, once the child is born, they can have him or her regularly checked for symptoms so that treatment can begin as early as needed. And they will want to keep up on the latest developments in the treatment of CF, because medical research may well lead to better treatments in time to help their child.

Based on his own family experience, however, Carlos may be determined not to have a child with CF. In this case, the couple has other choices. One possibility is to use an egg or sperm donor who does not carry a CF mutation. Another possibility is *ex utero* genetic testing. Mollie's eggs and Carlos's sperm would be mixed together. Cells from any eggs that become fertilized would be removed for DNA analysis. The embryos that do not carry genes with the CF mutation could then be implanted in Mollie's uterus. The child would be theirs, and he or she would not develop CF.

Complications

There are many other factors that complicate the decisions Mollie and Carlos must make. Suppose Mollie takes the test and it is positive. Suppose also that she and Carlos decide to go ahead and have a baby through *in vitro* fertilization, using either a donor who does not have the CF form of the gene or their own sperm and egg along with *ex utero* genetic testing. They will have to face the fact that this procedure can cost tens of thousands of dollars and may not be covered by their health insurance. *In vitro* fertilization also has a high failure rate and may take many tries before it works. This means a lot of time-consuming visits to medical offices. Mollie and Carlos will have to decide how long to keep trying if *in vitro* fertilization doesn't succeed right away.

If the couple decides to go with an egg or sperm donor, they will have to decide which of them gets to contribute their genes to their future child and which does not. They also will have to select a donor—either a friend, a relative, or a person unknown to them. They will have to decide what kind of relationship to have with their donor.

Mollie and Carlos also have to realize that even if they do everything in their power to avoid having a child with CF, they could still end up with a sick baby. After all, CF is only one of many possible genetic disorders. It would be far too costly and time consuming to test for all of them. Besides, there is no test for many genetic disorders at the present time. It's also important to remember that many health problems do not have genetic causes. For example, a difficult delivery could cause medical complications in the child. Whatever Mollie and Carlos do to add a child to their family, they have no guarantee that he or she will have perfect health.

In the past, there were few options for couples like Mollie and Carlos. Medical advances have opened up an overwhelming number of choices. The same is true for couples that have disorders other than CF in their family trees. As more genes involved with disorders are located, more screening tests will reach the market. Their use may be encouraged by the companies that make them, by many people in medicine, and by popular demand. Soon, all couples planning to have babies could face decisions like those that are before Mollie and Carlos.

The Possibility of Endless Decisions

What if you could decide ahead of time the features of your baby, such as the hair color and body shape? Scientists believe that prenatal testing may someday be used not only to avoid disease, but to select for desired features.

In one way, this already is being done. Some parents are using prenatal tests to choose the sex of their child. In some countries in which the culture values boys more than girls, ultrasound and amnio are used mainly to check the sex of the fetus. If the fetus is a girl, it is aborted. In the United States, sex selection is condemned by most people. However, some parents do it anyway.

At the present time, genetic testing does not reveal much else about a child's features. There could come a time, however, when genetic testing makes available endless choices. Parents will then have many more decisions to make—starting with the decision as to whether it is right to make such choices.



Genetic testing has another important use besides screening for disorders and traits. It also can be used for personal identification. You'll read about this in our next chapter.



Chapter 5

Donita Should Cooperate with the Police (or should she?)



The body of a young woman was found in the locker room of the factory where Donita works. Police say the woman was stabbed. The only clues are some strands of hair clutched in the hand of the victim. The hair is not hers, so police think it belongs to the murderer.

According to the factory guards, no outsiders were in the building at the time of the murder. For that reason, police believe the killer is one of the 500 women who work there. But which one? To find out, the police decide to do a mass DNA screening. They ask each worker to give a saliva sample. They want to compare the DNA from the hair to each worker's DNA. If they find a match, chances are they will have the killer.

Donita was friends with the woman who died. For the sake of her friend, Donita feels that she should give police a saliva sample. She figures that it is a painless and simple thing to do. More importantly, she wants the murderer to be found, and she realizes that the DNA screening will flush out the killer only if everyone cooperates. Still, the whole thing makes her uncomfortable. She believes that you are innocent until proven guilty, not the other way around. Donita didn't do the crime, and the police have no reason to suspect she did.

If you were Donita, what would you do?

DNA typing at crime labs can aid in the identification of people, just like fingerprints.



Everyone has a unique set of fingerprints, which is why fingerprinting is so useful for identifying people. For nearly 100 years, fingerprints have been used to track criminals. They also have been used to identify murder victims and soldiers killed in combat.

Fingerprints aren't always helpful in catching criminals, however. People who commit crimes often remember to wear gloves or at least to wipe away their prints. Even when police find a print, they can only compare it to the ones they have on file. If the culprit has never been arrested before, police won't find a match.

Using fingerprints isn't always useful for identifying bodies, either. Prints can't be taken from a badly damaged corpse such as one burned in a fire, torn apart by a bomb, or decayed. Even when you can get good prints, you need something to match them to. Unless you have an idea of who the person might be, and that person's prints are in records somewhere, the fingerprints from the body aren't of any use.

This is why there is so much excitement about **DNA fingerprinting**, or **DNA typing**, as it is also called. In many ways, DNA typing is a much better identification tool than prints from fingers. The actual process involved in DNA typing is quite complicated. What it does, however, is rather simple: It turns each DNA sample into a set of lines, like the bar code you find on the price tags for store products. The lines of one DNA sample can be compared to the lines of another sample to see if they are alike.



A sure match between two samples can be made only if entire DNA sequences are compared. That's such a huge task that it's not yet possible. So what DNA technicians do instead is compare several sections of DNA. If all the tested sections match, technicians can use mathematical formulas to estimate the odds that both samples come from the same person. DNA testing cannot absolutely prove a match, but it can come very close.

One of the great advantages of DNA typing is that there are so many ways to get a "print." You can use hair, blood, saliva, semen, skin, and nail clippings, because they all are made up of cells containing DNA.

For identifying bodies, DNA typing is better than fingerprinting because DNA lasts longer. After someone dies, the flesh decays quickly. This makes it difficult to get fingerprints. However, bones, teeth, and hair last a long time, and DNA typing using these materials can be done long after death.

DNA can also be analyzed for special information that fingerprints don't give. For example, DNA can be used to tell whether two people come from the same family. DNA can also be examined for important clues about persons, such as their gender and other physical characteristics. This might be done if, for example, some bones are found, and you want to figure out whom they belong to.

Uses for DNA Typing

DNA typing was first introduced in the early 1980s. Here are some of the ways it has been used since then:

- ▼ *To prove innocence.* DNA typing has been submitted as evidence in thousands of cases in the U.S. and other countries. In about one-third of these cases, it has been used to prove people innocent by showing that their DNA does *not* match the sample found at the crime scene. It also has been used to prove the innocence of people behind bars, including some death row inmates. For these inmates, DNA typing did not exist or was still too new when they were first tried. DNA evidence can last for years, for example, in semen stains on clothing. Lawyers have used this evidence at retrials to show that their client could not be the guilty party because his or her DNA type does not match the evidence.

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- ▼ *To prove guilt.* It is harder to use DNA as evidence to convict a person because juries need to find the defendant guilty “beyond a reasonable doubt.” DNA typing by itself leaves some doubt because there is always the chance that someone else besides the accused has matching DNA for the sections that were tested. There also is the chance that someone “planted” the DNA to pin the crime on the accused or that the testing lab has made a mistake. However, testing labs have improved their procedures to reduce the risk of false matches. Lawyers have learned how to combine DNA typing with other evidence to strengthen their case. For these reasons, prosecutors are becoming more successful at using DNA to pin the accused to the scene of a crime.
 - ▼ *To identify relatives.* Children of foreign-born residents of the U.S. and many other countries are allowed by law to enter and live here. Immigration officers have sometimes tried to block the entry of people they suspected were not really the children of legal residents. DNA typing has been used to prove a family relationship and allow legal entry.
 - ▼ *To prove fatherhood.* DNA typing has been used to prove or disprove **paternity**, that is, whether a man is the father of a child. It has been used in cases where the woman is suing for child support from a man who denies that he is the father. It also has been used in cases where a man wants to share custody of a child but the woman denies that he is the father.
 - ▼ *To identify bodies.* DNA typing has helped identify numerous murder and accident victims. For example, DNA typing was used to identify one of the victims of the 1995 bombing of the federal building in Oklahoma City. Long after all the bodies of the known victims were recovered, a leg was found in the rubble. DNA testing concluded that it belonged to an African-American woman. They used this clue to help identify her.
 - ▼ *To identify soldiers.* The U.S. military used to rely on dog tags to identify the remains of soldiers. Now it uses DNA typing. Blood and saliva samples are taken from new recruits and stored. If that soldier dies in combat and the body is too damaged to identify, DNA from the body can be compared to the DNA in the stored samples. DNA typing was first used to identify soldiers killed in the Persian Gulf War.

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- ▼ *To uncover history.* Examining the DNA of people long dead has been used to reveal information about the past. For example, DNA testing was used to identify the bodies of Czar Nicholas II and his family. This royal family was murdered at the beginning of the Russian Revolution in 1917, and the bodies were never found. In 1995, researchers used DNA typing to confirm that the bodies in a mass grave belonged to members of the Czar's family.
 - ▼ *To study human evolution.* Scientists are collecting DNA samples from people worldwide. They also are collecting DNA from the preserved skeletons of humans who lived thousands of years ago. They are using this information to better understand how the first humans on earth evolved into the many different peoples of the world.

Issues of Privacy

Computers are part of what makes DNA typing such a powerful tool. They can store information from millions of DNA samples. Plus, they can rapidly search through all of this information to find matches. It is this power that concerns Donita, the woman who doesn't know if she should take part in the DNA screening.

If Donita cooperates, her DNA print will go into the police's **data bank**, along with prints from all the other factory workers. The prints will be compared to the DNA from the hairs found in the victim's hand. Unless those hairs came from Donita's head, her DNA sample should remove her as a suspect.

But her DNA sample may not be removed from the police computer. It may become part of a permanent file. This means that every time the police search their computer to find a match for some DNA evidence found at some crime scene, they will be checking her DNA print. In essence, she will be a permanent suspect.

From Donita's point of view, this is a permanent invasion of **privacy**. "Privacy" has many definitions. One definition is "the right to be left alone." As long as her print is on file, Donita is not being left alone. She may never be approached by the police again, but they will always be "looking" at her.

Another definition of “privacy” is “the right to decide for yourself what information others can know about you.” By giving police her DNA, Donita will be releasing all sorts of information about herself. There is the possibility that they will not only type her DNA, but also test it to learn many things about her. The effect on Donita may be a feeling of loss of control over personal information.

Another concern for Donita is whether the police will keep the DNA information they have on her secret from others. How will the police safeguard these files? Will they permit the use of the files for purposes that don’t have to do with law enforcement?

Finally, if privacy is the right to decide what information others can learn about you, it also is the right to decide what information you learn about yourself. If Donita’s DNA sample is typed, she may learn some things by accident that she never expected to find out. Perhaps she will learn that she is the carrier of a gene mutation that could lead to disease. Perhaps she will learn that she doesn’t share certain genetic traits with her parents and therefore must be adopted. There is all sorts of information that DNA can reveal that people may not want to find out.

Controls on DNA Files

Mass DNA screenings like the one at Donita’s factory have been used by police in several regions of the world, including England, Wales, and Germany. A new law in England allows the police to take hair or saliva samples from suspects for DNA typing, even without permission. England also has created the world’s first nationwide DNA computer data bank.

Mass DNA screening to solve crimes has not yet happened in the U.S. This country has a strong tradition of protecting privacy. The Fourth Amendment to the Constitution protects citizens against “unreasonable search and seizure.” In Donita’s case, there is no reason to suspect her of the murder, except that she worked at the factory where it took place. Therefore, taking her DNA might be ruled an “unreasonable search” by a U.S. court. Also, even though she is being asked to volunteer a blood sample, the courts may feel that this is an “unreasonable seizure” because she is being pressured to give a sample.

However, we don't know for certain how U.S. courts would rule. There hasn't been a court case around this issue yet, so we just don't know. It's possible that someday mass DNA screenings could become a common tool of U.S. police.

Even without mass DNA screenings, however, U.S. law enforcement DNA data banks are growing. Many states require convicted felons and sex offenders to give blood or saliva samples for DNA typing as a condition for parole. The idea is for police to be able to use these data banks to catch repeat offenders. The FBI also is building a DNA data bank of criminals. It is possible that DNA samples may someday be taken from people who are convicted of misdemeanors. This means that even if you get stopped for speeding, your DNA could end up in police files.

It is also possible that information from your DNA could end up in other types of data banks. Today, there are many instances where you have to release personal and medical information about yourself. This happens when you apply for a job, for life or health insurance, for credit, for financial aid, or for benefits from the government. If the results of any DNA tests become part of your records, you may have to release the information in order to obtain needed services.

Right now, there are no laws concerning DNA data banks. There is no law which says that a blood sample collected for one kind of DNA testing can't be used for another purpose. There is no law that limits data bank employees from snooping in your files. There is no law that gives you the right to check your DNA file to find out what information is there or to make sure the information is correct.

Some people say that we need to come up with rules for how DNA data banks operate. They say it would be easier to set up the rules now, before the practice of storing and sharing DNA information in computers grows any larger. But technology often moves faster than lawmaking. People may not demand this privacy protection until after they have had their DNA on file somewhere.

Our growing ability to gather DNA information is making many changes in our ways of life. However, it is not just we humans who are affected. The world is also changing for other animals and for plants as well. We look at these changes in our next chapter.



DNA data banks contain files that could be used to keep track of a person.





Chapter 6

John and Elsa Will Profit from Biotech Farming (or will they?)

Elsa and John are dairy farmers. They need to make a decision that could mean whether or not they stay in business.

They need to decide whether to inject their cows with a drug that increases the amount of milk their cows produce. The drug was developed through genetic research.

The government has approved the use of this drug. Hundreds of studies show that milk from cows given the drug is safe and healthy to drink.

However, many consumers are afraid of drinking milk from treated cows. They don't trust the studies that say the milk is safe. They point out that sometimes scientific claims are proven to be wrong as new evidence is collected.

Elsa and John run a family farm. They pride themselves on being "natural" and "old-fashioned" farmers. However, if they don't use the drug, their farm may not be as productive as other dairy farms that do use it. On the other hand, they really can't afford any more expenses. They already are having trouble keeping up.

If you were Elsa or John, what would you do?

At the beginning of this book, we made three statements about you. First, we said that you are like *no one* else. Second, we said that in many ways you are like *some* other people on earth. Third, we said that in some ways you are like *every* other person on earth.

Genetically speaking, all three statements are true. Now here are three statements that are even more interesting. Genetically speaking, we human beings are like *no other* species. Yet in many ways, we are like *some* other species on earth. And in some ways, we are like *every* other species on earth.

There are some genes that are found only in human beings. However, there are some genes that are found both in humans and in other species. And some parts of our DNA are found in nearly every other species. All but a small fraction of human DNA is the same as chimpanzee DNA. The DNA of mice, rats, and rabbits have much in common with human DNA, too.

The Human Genome Project has the goal of learning about the human genome, but researchers involved also are studying the genomes of a form of yeast, a fruit fly, a mouse, a plant, and many **bacteria**. (Bacteria are very small, single-celled life-forms that can reproduce quickly.) Researchers are studying the genomes of these species to learn about the similar, but more complicated, genome of human beings. What they learn from the genes of one species is helping them understand how genes work in all species.

Genetic Engineering

Have you ever tried to figure out how something works, for example, a clock or a motor? One way to learn is by taking the object apart. Genetic researchers do the same thing. They cut apart the genome to figure out what the individual parts do. Researchers have found ways to slice genes out of a genome. They have learned how to make changes to a gene and how to replace one gene with another. This “cutting and pasting” is called **genetic engineering**, and it’s a very useful way to do research.

Say, for example, that researchers want to find out what different genes do in a particular kind of flowering plant. They can take a seed from that plant and use a special technique to get inside its genome. Once inside, they can cut out a single gene. Then they can let the seed grow to see what kind of plant it makes. If the plant that develops doesn't have any petals, it means the gene they cut out is important for making flowers. If the plant ends up with too many petals, it means the gene is important for stopping petal growth. Researchers repeat this experiment many times, cutting out different genes each time. In this way, they are able to match genes to the instructions they give.

Researchers then use this information to learn about the genes of other species. For example, finding the gene that controls petal growth in one plant helps researchers find similar genes in other plants. These clues also can help researchers find genes that control growth in animals.

Biotechnology

Genetic engineering is important for basic research, but it also is at the heart of a whole new industry called **biotechnology**, or “biotech” for short. Biotechnology is the use of living things to make products. Biotechnology is not new. People have long known how to use yeast to make bread rise and how to use bacteria to ferment beer and wine or to age cheese. In today's biotechnology industry, modern biological tools are used to make products.

One such tool is genetic engineering of plants and animals. In the past, humans changed many species through **selective breeding**. They saved the seeds from their best plants for use as next year's crop, and they took the best animals from their herds to mate together. Through trial and error, and over many generations, this process shaped the traits of numerous species. Many of today's food crops, such as wheat and rice, were developed through thousands of years of selective breeding. So were farm animals such as cows and pigs and pets such as the many kinds of cats and dogs.



The genetic engineering that is done in biotech is far faster and more precise than selective breeding. By inserting, removing, or making changes to genes, new forms of plants and animals can be created in one generation. What is even more awesome about biotech is that it can easily overcome the barriers between species. Many new biotech products are made by transferring genes from one species into another. A **transgenic** plant or animal is one that contains genes from another species.

While many biotech creations are still in the experimental stage, a growing number are already on the market, both in the U.S. and in other countries. Here are some examples of what's coming out of biotech labs:

- ▼ *Improved forms of crops.* Experiments are under way to produce wheat, cotton, rice, and other crops that resist insects and disease. This could reduce the need for insecticides and pesticides, which can be expensive as well as harmful to the environment. Researchers also hope to create new forms of crops that give a bigger harvest or that contain more protein and are therefore more nutritious.
- ▼ *Super-sized and super-fast-growing animals.* Genes that instruct for growth in humans and cows have been inserted into mice, pigs, sheep, and fish. Through these experiments, researchers are trying to figure out how to increase the amount of food that farms and fisheries can produce.
- ▼ *Livestock that produce more young.* Researchers hope to develop animals that have bigger litters and birds that lay more eggs. This would be a way to increase food production.
- ▼ *More healthful foods.* Coffee plants are being engineered to produce beans low in caffeine. This would be an alternative to using chemicals for making decaffeinated coffee. Beef cattle are being engineered to produce low-fat meat, which would be healthier to eat. Dairy cows and sheep are being genetically altered so that their milk does not contain lactose, which many people cannot digest. Experiments also are under way to engineer cows to produce milk that is more like human breast milk. This would mean that women who do not nurse would have a better formula to feed their babies.



Genetic engineering can produce crops that are more resistant to disease or that taste better.



*Square tomatoes?
Some farmers want to
raise tomatoes that are
easier to pack in boxes
than round ones are.*

- ▼ *Vegetables that stay ripe longer.* Researchers have engineered tomatoes so that they take longer to rot. Normally, tomatoes that are grown for the market have to be picked green so that they don't spoil before reaching the stores. The new tomatoes can be left to ripen on the vine, which gives them a better flavor. Researchers also are working on slow-to-rot peas, peppers, and tropical fruits.
- ▼ *Plants and farm animals that can survive under harsh conditions.* Biotech companies are trying to develop crops and livestock that can survive in areas of the world that would not normally be farmed, such as deserts, very cold lands, polluted grounds, and salty land near the sea. The goal is to produce food closer to the people who need it, preventing starvation as the world's population grows.
- ▼ *Bacteria that eat up oil spills and toxic wastes.* Researchers hope that pollution-eating bacteria will help solve a whole host of environmental problems.
- ▼ *Animals that can serve as organ donors for humans.* Researchers are putting human genes into pigs and baboons. They are trying to design animals whose organs are not rejected when transplanted into the human body. This could solve the problem of long waiting lists for people in need of new hearts and other organs.
- ▼ *Transgenic plants and animals that make important drugs.* Researchers are seeking to produce greater quantities of useful medicines at less expense. That way, the medicines could be available to more people who need them. Tobacco plants have been engineered to produce a drug that helps fight AIDS. Sheep embryos have been genetically altered so that when they are born and ultimately mature, their milk contains substances that can be used as medicines.
- ▼ *Species that create new materials.* Plants are being created that release a plastic like substance on their leaves. This substance could be a substitute for oil, which is becoming more scarce and also is expensive to pump out of the ground. Silkworm genes have been inserted into bacteria. As the bacteria grow, they create a new kind of thread that is as soft as silk, but as strong as steel.

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- ▼ *Mice that are custom made to test for human diseases.* Researchers have genetically altered mice to remove the genes that make them resist disease. These mice are used to test treatments for **immune disorders** such as AIDS. (An immune disorder interferes with the body's ability to fight infection.) Other mice have been genetically altered to carry genes whose instructions lead to disease. The mice are then studied in order to better understand the disease. Medicines to control the disease also can be tested on these mice. Thousands of different kinds of genetically altered mice, as well as rats and other animals, have been created to aid in medical research.
 - ▼ *Foods that contain vaccines.* Researchers have successfully developed tobacco and potato plants that contain vaccine proteins. They are now working to develop bananas that would give vaccine protection for a variety of diseases. Doctors hope that vaccines delivered through fruit would be less expensive and an easier way than shots to give vaccine protection to people in poor countries.
 - ▼ *Food ingredients that can be grown in a laboratory instead of in the field.* These ingredients include dyes, flavors, and enzymes that are important for processing food. Through biotech, it may be possible to manufacture such ingredients more cheaply and in greater quantities than through traditional means.



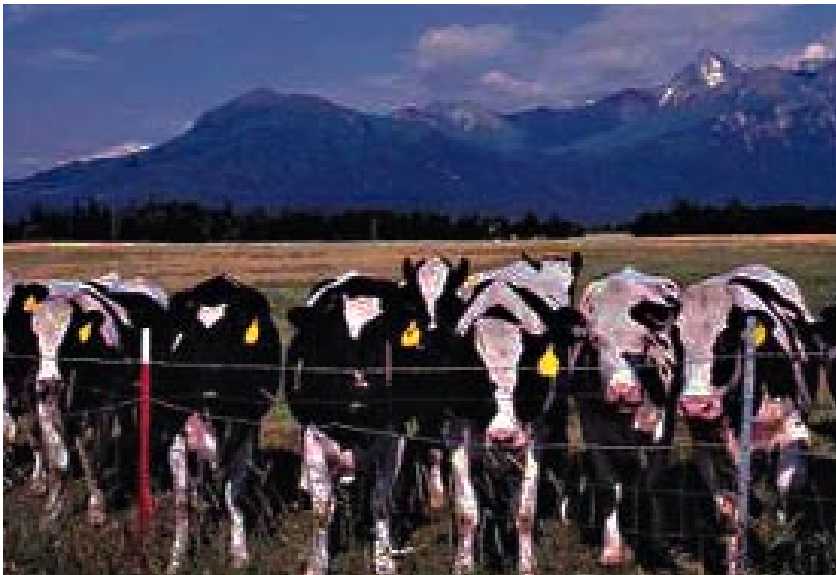
Pros and Cons of Biotech Farming

Research labs in nearly every country of the world have jumped into biotech. Big corporations, governments, and universities have invested in it, and hundreds of small new companies have entered the field. Billions of dollars are being spent on biotech research, and billions of dollars stand to be made from the new products.

Biotechnology is having a huge impact in many areas of our lives, from medicine to industry. Agriculture also is being affected. Farmers are having to decide how to keep up with the changes. That is the issue for Elsa and John, who are thinking about using a genetically engineered drug on their dairy cows.

The drug they are considering is an artificially produced **hormone**. Hormones are proteins produced by organs of the body that trigger activity in other locations. Cows produce a natural hormone called bovine growth hormone, or BGH, that causes them to make milk.

Researchers have found the gene in cows that triggers the release of BGH. They have figured out how to **clone** the gene in order to produce BGH artificially. “To clone” means “to make an exact copy of.” Some cells are removed from a cow, and the gene for BGH is cut out of their genome. The gene is then injected into bacteria. Bacteria reproduce very quickly. As each new cell of bacteria is made, a new copy of the gene also is made. In this way, millions of copies of the gene are produced in a short time. With millions of copies of the gene, lots of BGH gets produced. The BGH is then strained out of the bacteria and sold as a drug. Giving cows this drug increases the amount of milk they produce by as much as 15 percent.



More milk from their cows could mean more money for Elsa and John. However, to make that extra money, they will have to spend more up front. There will be the cost of purchasing the hormone. Then, there will be the added costs of keeping the cows fit. This is because some studies suggest that cows treated with the hormone suffer more health problems than untreated cows. Also, there will be the cost of replacing their herd more frequently. This is because treated cows “give out” more quickly.

Elsa and John also have to decide if consumers will want their milk. Many

studies say that the milk from treated cows is perfectly safe. The government also runs an inspection program for milk to make sure that it is safe. Even so, some people are concerned that the milk may contain trace amounts of the hormone. They also fear that the milk may be tainted by the extra doses of antibiotic drugs these cows need to stay healthy.

Other Concerns About Biotech Farming

Some people are against the development of products like BGH because they say that in the long run it will hurt family farms like Elsa and John's. Large corporate farms can afford the added costs of using BGH, but smaller ones cannot and may be pushed out of business. BGH also may lead to the overproduction of milk, causing milk prices to drop. Large farms with big volume can survive on smaller profit margins, but small farms may not be able to.

Animal rights groups also have been critical of BGH because it is hard on the cows. According to them, BGH is tailor made for a "factory" style of farming in which animals are penned up, closely controlled, and pushed to overproduce. These groups say that farms can succeed without BGH through well-managed selective breeding and by more humane and healthful treatment of their livestock.

Similar concerns are raised over crops that have been engineered to resist pests and weeds. On the one hand, farmers raising these kinds of crops would probably not have to spray so much to control their fields. This could save the farmers money and be better on the environment. On the other hand, mutations of the pests and weeds could develop that would overcome the resistance of the genetically engineered crops.

Furthermore, there is the possibility that the engineered crops could cross with closely related plants. This could lead to new species of weeds that are even harder to control. Sooner or later, pests and weeds could once again be a problem. If that happens, farmers would have to use more spray. Or they would have to invest in new seed from a new generation of engineered crops.

Arguments also have been raised against genetic engineering for more productive crops and livestock. According to this argument, we don't really need to produce more food. What we need to do is overcome politics and distribution problems so that food gets to hungry people. Biotech promises to bring food closer to people who need it by creating crops and animals that can be raised in whole new climates. However, this could lead to the destruction of even more wildlife areas.

Some people argue that instead of using biotech to increase the food supply, we should change the world's eating habits. One suggestion they have is that people should eat less meat, because cattle require so much land for grazing. More meals could be produced off that land if it were used for raising crops instead.

Those who support biotech farming respond to all of these arguments by saying that we can't go back in time. The world's population is growing rapidly. It's too risky to assume that we will have enough food for everyone by persuading some people to change their diets. A better solution is to use biotech to develop more efficient ways of making food. If family farms disappear in this process, then that is the price that must be paid.

Supporters of biotech farming also respond to the concerns about the treatment of animals and destruction of wildlife areas. They say that these problems are not new, and biotech farming should not be the scapegoat. They say that problems should be addressed and solved, but that condemning biotechnology is not the answer.

Big Questions About Biotech

The issues raised by biotech spill over into many areas beyond farming practices. One big question that biotech raises is whether it is right to alter the genes of animals. Another big question is whether it is right to make transgenic animals.

The scientists who do this kind of research say that the benefits to humans will be enormous. They also point out that animals have long been used in service to people. As an example, they point out that we raise pigs for bacon, so why not raise them to be organ donors? They argue that genetic engineering is just a new form of selective breeding, which humans have been doing for thousands of years. They also point out that the transfer of genes across species occasionally happens in nature, so it is not "unnatural" for humans to do it.

Others say that such a human-centered attitude is wrong. They say that animals are more than a collection of cells to be tinkered with at will. Rather, they are unique living beings with the right to exist for themselves. They also say that genetic engineering is potentially more harmful than selective breeding, because it can be used to change the traits of a species so quickly.

Another big question is whether we know enough to control the effects of our biotech experiments. There is a saying that in nature you can't change just one thing. Altering one trait of a species may affect it in more than one way. Creating transgenic bacteria, bugs, plants, or animals may have unintended effects. Some people say that researchers don't know enough about how genes operate to be doing this kind of work. They say that the researchers are "playing God." These people recognize that useful products are coming out of biotech. However, they worry that just one experiment gone wrong could cause a lot of harm.

Researchers respond that they have strong controls in place to make sure that their biotech experiments and products are safe. They also point out that many different government agencies regulate the industry. Finally, they say that it is easy to understand the questions about safety, but it isn't so easy to understand the answers because they involve so much science. By educating the public, biotech experts hope to win more support for their industry.

The tools of biotech, now that they have been discovered, are not going to be put aside. The question is how we will use these tools—recklessly or carefully. The tools of biotech also are affecting the development of one species in particular—human beings. That's discussed in our final chapter.



Chapter 7

Dr. Lu's Patients Have the Right to Be Tall (or do they?)

Dr. Lu has two patients with the same problem, but she isn't sure if she should treat them both. The patients, Tim and Rico, are seven-year-old boys who are very short for their age.

Tim will never grow much taller than 5 feet because his body does not produce enough of a hormone needed to grow. When he is an adult, Tim will be much shorter than his mother and father, who are both closer to 6 feet.

Rico will never grow much taller than 5 feet either. Rico will be short because he has inherited his body build from his parents, who are both about five feet tall.

Researchers have used genetic engineering to produce a growth hormone. Both sets of parents want this growth hormone to be prescribed for their sons to help them grow taller. They want this because they feel that there are many advantages to being tall.

Dr. Lu realizes that genes play a role in the height each child will reach. Tim will be short because of a single mutation in one gene that instructs for the production of a growth hormone. Rico will be short due to the many genes he inherited from two short parents. Despite this difference, the end result for both boys will be the same.

Dr. Lu is thinking about prescribing the hormone for Tim, but not for Rico. However, she wonders if she is being fair. If you were Dr. Lu, what would you do?

When you fall ill, you sometimes need to go to a doctor to find out what is wrong. At the doctor's office, they will observe your symptoms and examine your body. They may look inside you using X rays and other equipment. They may do tests on your blood or urine, to see whether anything is wrong with your cells or the way your body is working. They also may do something else: look inside your cells at your genes. Every day, genetic research is being applied in new ways to help diagnose health problems.

Someday, it also may be possible to *correct* health problems by going inside cells to the genes. Treating disorders by altering genes is called **gene therapy**. It will work something like this. When you have an illness, your doctor will determine whether the problem is caused by a mutated gene that is giving out faulty instructions for the production of a needed protein. If so, new DNA will be inserted into some of your cells. This new DNA will correct the gene's instruction for making the protein. If the treatment is successful, the repaired gene in these cells will go to work, giving out the proper instructions so that the protein is produced.

Cystic fibrosis is one disease that researchers are trying to cure through gene therapy. In Chapter 4, we explained that with CF the lungs become clogged, making it hard to breathe. The problem is caused when a gene gives faulty instructions for producing the protein that helps make the mucus lining of the lungs.

Doctors are trying to move corrected copies of this gene into the lung cells of CF patients, using a **virus**. We usually think of a virus as causing illness. However, the kind of virus used in this experiment is harmless. Using special techniques, copies of the corrected gene are inserted into the virus. Then the virus is sprayed up the nostrils of the patients. The virus attaches to cells inside the nose and lungs and reproduces by inserting part of itself into them. As it inserts its DNA into these cells, it also inserts the corrected gene. Hopefully, the corrected gene will take over in enough cells so that the needed protein is produced.

Gene therapy is also being tried with a disorder called **severe combined immunodeficiency (SCID)**. This disorder occurs when the body fails to produce a particular enzyme. Without the enzyme, a person cannot make the special blood cells that resist infection. A few young children with this disorder have been treated with cells altered to carry the genetic instructions for making the enzyme.



It is too early to tell whether these treatments will work. Hundreds of research trials are under way using gene therapy. None has yet been able to claim complete success, although a lot of valuable things are being learned. Even so, gene therapy is still so experimental, that it is being tried only on patients who have diseases for which there are no other cures.

It's also important to realize that gene therapy may never work for a wide range of health problems. It may be too difficult to use genetic therapy for disorders that involve the actions of many genes. Also, for many health problems in which genes are involved, the genes are only partly responsible for what's wrong. In such cases, gene therapy may be only part of the solution. Gene therapy also may be of little use in treating medical problems that have no genetic cause, such as broken bones or wounds caused by an accident.

Germ-Line Therapy

The kind of gene therapy we have talked about so far will be for people who are already born. That is, it will fix some of the genes at work in a part of a person's body. It will not affect the genes that a person passes on to the next generation. However, even that may be possible some day. The kind of treatment that could change the genes you pass on to your children is called **germ-line therapy**.

From Chapter 2, you may recall that germ cells are the special cells that divide to form eggs and sperm. Researchers are figuring out how to alter the DNA in your germ cells. If they succeed, this means that they would be able to alter the DNA that is copied and passed on through your eggs (if you are female) or your sperm (if you are male).

With germ-line therapy, genes could be "corrected" in the egg or sperm you are using to conceive. The child that results would be spared certain genetic problems that might otherwise have occurred. It may even be possible someday to use germ-line therapy to remove a disorder from your family tree forever. Your children would not inherit the problem gene. Neither would your grandchildren or your great-grandchildren.

Germ-line therapy is a long way off. However, it already is very controversial. In fact, it is so controversial, that the U.S. government currently does not allow federal funds to be used for germ-line experiments on human patients.

Most people who have thought about germ-line therapy do not oppose the idea of using it to help families rid themselves of the genes for terrible diseases. However, they are concerned because making changes to the germ line of one person can affect many people who are that person's descendants. They say that perhaps it is not right to make changes to a germ line, because some of the people who will be affected are not even born yet and therefore cannot give their consent. An even bigger concern is that making changes to germ cells could disrupt the development of the embryo or fetus in unexpected ways. For these reasons, most people feel that germ-line therapy should not be used until we fully understand its long-term effects and have addressed the ethical questions it raised.

Genetically Engineered Medicines

Although gene therapy is still experimental, in other ways genetic research already has changed how medicine is practiced. This is because of the genetically engineered drugs that are now available through biotechnology.

Take, for example, the treatment of diabetes. In the past, the only way to get insulin for diabetics was to process it from pigs and cattle. Then researchers learned how to make insulin by cloning the human gene that carries the instructions for making insulin.

Cloning and other techniques of genetic engineering have had many positive results. Genetic engineering has helped increase the supply of medical products and lower their costs. It has resulted in new drugs being created. Another benefit of genetically engineered materials is their purity. This is important, since there have been cases in the past where medical products processed from animals or human donors carried disease.



Human growth hormone is one of the medical products that can now be manufactured through genetic engineering. In the past, its only source was recently dead human donors. Getting human growth hormone in this way was difficult and controversial. It also did not recover very much of the hormone. Furthermore, there was a risk that hormones from dead bodies might be contaminated and pass on diseases. With genetic engineering, human growth hormone can now be produced in pure form in large quantities. This has made the hormone more widely available. That's why Dr. Lu faces her decision on treating Tim and Rico, the boys who are both very short.

Without treatment, neither boy will end up much over five feet tall. There is nothing unhealthy about being only five feet tall, of course. However, Dr. Lu may feel that Tim should have treatment because his one gene is not working normally. She may even feel that Rico should have treatment because his normal genes will cause him to be abnormally short.

Suppose, however, that Dr. Lu's next patients are children who will grow to be only 5 foot 4 inches or 5 foot 6 inches. If their families want them to be taller, what should she do? Where does she draw the line? It's even possible that as people hear about this growth hormone, they will demand it for their tall children to make them even taller. What will Dr. Lu do for families that want their boys to be seven-foot-tall basketball stars?

One thing that Dr. Lu has to consider is that the treatment is not quick and easy. For it to work, the boys will have to receive a great many shots over several years. The treatment appears to have side effects. For example, it may cause bad cases of acne that leave scars. Also, the treatment doesn't guarantee how much the boys will grow. Studies suggest that the treatment works better for children like Tim, who has a single mutated gene responsible for his stunted growth, compared to children like Rico, who has many genes contributing to his short build. Even so, all those years of shots may give Tim a few extra few inches and Rico even less.

Dr. Lu also must consider the fact that the treatment would be performed on children. Genetically engineered drugs are still new. It's possible that there are long-term side effects that no one knows about yet. Since Tim and Rico are children, they can't make the decision themselves. On the other hand, Dr. Lu can't wait until they are adults for them to decide, because the treatment needs to start while they are still growing.

So perhaps the decision rests with the parents. Yet before she turns the decision over to them, Dr. Lu must consider one more thing: whether the problem of being short is really a medical problem that deserves treatment. The parents may feel that if their children are taller, they will have more success. The question remains, however: What needs changing, the boys or the idea that short is bad and tall is good?

Eugenics

Genetic research is uncovering new ways to treat, cure, and even prevent many kinds of diseases and disorders. However, it is quite likely that the new techniques will be used in ways that don't always have to do with health.

In Dr. Lu's story, two families wanted a genetically engineered drug for their children not because the children were sick, but because they wanted them to be taller. Genetically engineered drugs, gene therapy, and germ-line therapy could open the door for lots of people to change how they or their children look. People may seek genetic treatments that will make them look younger, have more hair, or lose weight. If researchers ever figure out how genes control for behavior and ability, people may try to use that knowledge, too, for example, to improve their I.Q. or their athletic ability. There is nothing new about people wanting to improve themselves. What will be new is the opportunity to use genetic techniques to make those improvements.

There is a word that describes the use of genetic knowledge to improve the human race. The word is **eugenics**. "Eugenics" comes from a Greek word meaning "wellborn." For many people, the word has a bad ring to it. This is because eugenic ideas often have been used by people to claim that they are better than others.

That is what happened in Nazi Germany. Hundreds of thousands of people were sterilized, and millions more were killed, in concentration camps because the Nazis wanted to "purify" the German race. They targeted Jews and also Gypsies, homosexuals, and many others. Many of these people were victims of cruel and inhumane experiments designed to prove Nazi eugenic theories.

Even before the Nazis came to power, however, eugenic ideas were very popular in the United States and Europe. Many people in the first half of the 1900s believed that crime, poverty, and other social problems were the fault of people with “bad blood.” They also believed that people of “poor stock” were reproducing more quickly than people of “good stock,” leading to the decline of the human race.

The people who held these ideas considered themselves to have “good blood.” They were for the most part well to do, educated, white, Protestant, and descended from northern Europeans. People with “bad blood” were people who were different from them—poor, uneducated, of color, Catholic or Jewish, and descended from southern Europeans.

Some people who held eugenic ideas also were scientists. These scientists conducted research to support their theories. For the most part, their research was badly done and affected by their beliefs about the kinds of people who were good or bad. Even so, many states in the U.S. adopted laws to control “overbreeding” by people of poor stock. For example, thousands of prostitutes and black women were sterilized on the grounds that they were “feeble-minded.”

Eugenic ideas are popular even today. China has a law that forbids mentally retarded people from marrying if they have not been sterilized. Singapore offers cash rewards to well-educated women who have babies.

In the U.S., the eugenics laws from the first half of the century are no longer on the books. However, the beliefs still persist. One new way these beliefs are expressed is in the idea that poor people are poor because they have poor genes. This idea is not based on good science, but that does not prevent the idea from catching on.

A “Super” Race?

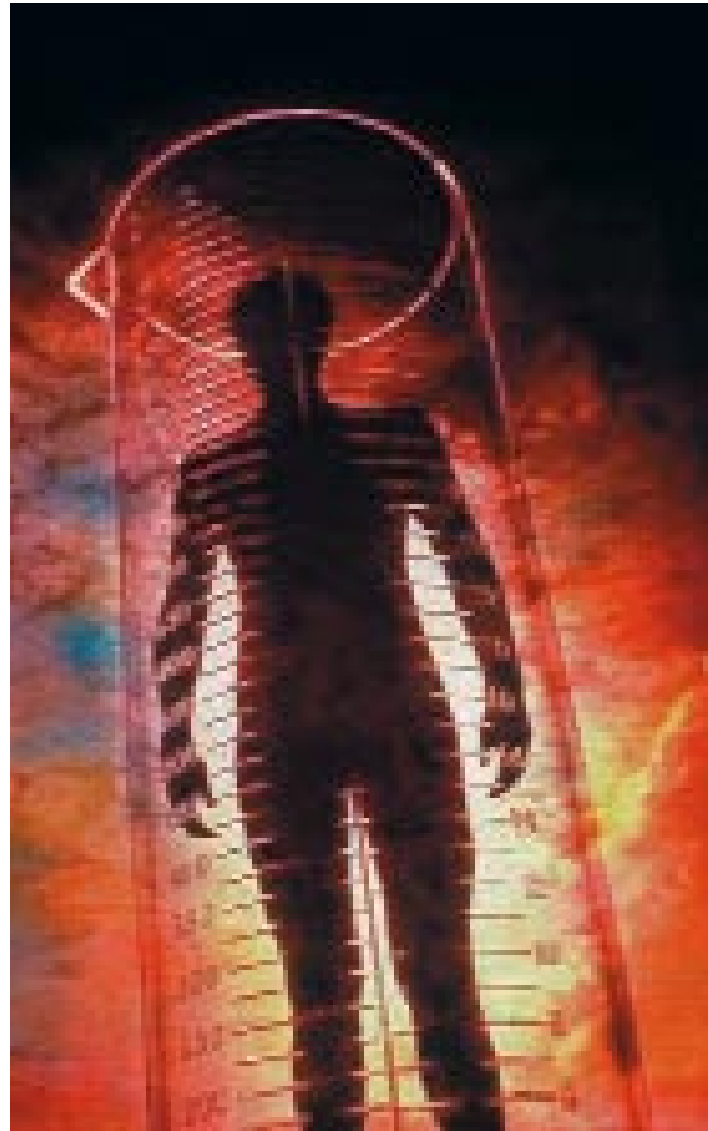
Some people fear that once we have the tools to tinker with our genes, we may be tempted to use them to design a “super” race of human beings. As a practical matter, this will probably never be possible. It’s one thing to use gene therapy to get rid of an unwanted gene or two. It’s a whole lot more to pick and choose the whole range of genes that make an ideal person.

First of all, you would have to decide what is the ideal. Then you would have to figure out which different genes come into play to make that ideal. And then you would have to figure out how to raise all the children so that they grow up to be ideal. Even if you could solve all those issues, you would still need the political power to make it happen. A grand plan to “improve” the human race would involve the government in personal childbearing and child-rearing choices. This would certainly be opposed by many and difficult to enforce.

So we may never make a “super” race. But in more limited ways, we may be able to shape our future. We may be able to spare ourselves and our descendants from terrible diseases and disorders. We also may be able to select some of the traits of our children. But do we want to? We also need to think about whether these choices will be available to everyone. It probably won’t matter too much if some people don’t get to select the eye color of their children. However, it will matter a great deal if some day only poor people suffer from terrible genetic disorders because they are the only ones who cannot afford genetic medicines and gene therapy.

We also need to worry about whether genetic technology will make us less accepting of people who are different. For example, if it is possible to predict and prevent the birth of a child with a gene-related disorder, how will we react to children we meet who have that disorder? Will we think, Why is this child alive? Will we think, Why didn’t the parents “do something” to prevent the child’s condition? Will we resent the medical and special education costs spent on the child? Will we put pressure on parents not to have “defective” children?

One of the important beliefs upon which this country was built is the idea that we are all “created equal.” We know from the study of our genes that we are indeed very much alike. But we are not genetically equal. And no matter how much we tinker with our genes, we never will be.



However, that doesn't mean that we don't all have equal rights. It's important to remember that what we believe in is as important as what science allows us to do.

Your Genes, Your Choices

In this book, we have talked about the many ways that genetic research is changing the world we live in. It's truly exciting. It's also overwhelming. You may feel that you have little control over the way that genetic research will be used, for good or for bad.

But you do have power. The way that society uses its knowledge of genetics will be shaped by the everyday choices its citizens make.

You help shape what happens through the way you express your beliefs and opinions and by the actions you take. You also affect what happens through your community efforts, working for the passage of laws or electing leaders who believe as you do.

You made a choice to gain some control of genetic issues by reading this book. Now you have the choice to remain informed. You have the choice to use your knowledge when making personal decisions that involve the use of genetic research. And you have the choice to participate when issues involving genetics are raised in your community.



Glossary

albino:	Having pale or colorless skin, eyes, and hair because the body does not produce enough pigment.
alpha-fetoprotein test (AFP):	A prenatal test to measure the amount of a fetal protein in the mother's blood. Abnormal amounts of the protein may indicate genetic problems in the fetus.
Americans with Disabilities Act (ADA):	A 1990 federal law that forbids discrimination against persons who are disabled.
amniocentesis:	A prenatal test in which cells surrounding a fetus are removed in order to examine the chromosomes.
artificial insemination:	The injection of semen into a woman's uterus (not through sexual intercourse) in order to make her pregnant.
bacteria:	Very small, single-celled life-forms that can reproduce quickly.
bases:	Distinct chemical ingredients found in the genetic material of all life-forms.
behavioral genetics:	The study of whether and how traits for behavior are inherited.
biotechnology:	The use of living things to make products.
carcinogens:	Cancer-causing substances.

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- carrier:** A person who has one copy of the gene mutation for a recessive disorder. Carriers are not affected by the disorder. However, they can pass on the mutated gene to their children. Children who inherit two such genes may be affected by the disorder.
- chorionic villus sampling (CVS)** A prenatal test in which cells surrounding an embryo are removed in order to examine the chromosomes.
- chromosomes:** Separate strands of genes, contained in the nucleus of a cell. Normally, chromosomes appear in corresponding pairs. A genome is made up of a complete set of paired chromosomes.
- clone:** To make an exact copy of.
- conception:** In reproduction, the point at which a sperm fertilizes an egg.
- crossing over:** Where a section of one chromosome switches places with the same section from the other chromosome of the pair. This sometimes occurs when a germ cell makes copies of its chromosomes before dividing.
- cystic fibrosis (CF):** A recessive genetic disorder affecting the mucus lining of the lungs, leading to breathing problems and other difficulties.
- data bank:** A collection of information organized so that specific facts can be retrieved as needed. Today, many data banks are organized on computers.
- disorders:** Problems in how the body functions. Health problems caused by mutations in the genes are referred to as genetic disorders.
- DNA:** The material inside the nucleus of cells that carries genetic information. The scientific name for DNA is deoxyribonucleic acid.

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- DNA fingerprinting:** A term for DNA typing. (See below.)
- DNA marker:** A gene or other fragment of DNA whose location in the genome is known.
- DNA typing:** The analysis of sections of DNA for purposes of identification.
- dominant:** Having power and influence. In genetics, a dominant gene is a gene that expresses its instructions.
- embryo:** An animal in the early stage of development before birth. In humans, the embryo stage is the first three months following conception.
- environment:** The nongenetic conditions and circumstances that affect a person's conduct and health.
- enzymes:** Proteins that trigger activity in the cells of the body. An enzyme is not affected by the activity that it sets off.
- ethical issues:** Questions concerning what is moral or right.
- eugenics:** The belief that information about heredity can be used to improve the human race.
- evolution:** The process by which all forms of plant and animal life change slowly over time because of slight variations in the genes that one generation passes down to the next.
- ex utero* genetic testing:** DNA analysis performed on cells of eggs that have been fertilized *in vitro*.
- fetus:** An animal in the later stage of development before birth. In humans, the fetal stage is the from the end of the third month until birth.

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- genes:** Units of hereditary information. Genes contain the instructions for the production of proteins, which make up the structure of cells and direct their activities.
- gene therapy:** The altering of genes in order to affect their function.
- genetic counseling:** Education and guidance offered by professional advisors in order to help people make informed decisions based on genetic knowledge. Genetic counseling is intended to help a person understand the meaning of specific information about his or her genes. It also is intended to help a person decide whether to have a genetic test performed or what to do with information provided by such a test.
- genetic determinism:** The false belief that a person's fate is determined solely by his or her genes.
- genetic engineering:** The artificial introduction of changes to the genes in a cell.
- genetic expression:** The effects of a gene's instruction on the cells of the body.
- genetic linkage study:** Examination of the DNA of family members to determine who may be at risk for a genetic disorder occurring in the family tree. Doctors look for variations that consistently appear in the DNA of family members with the disorder. These DNA variations may or may not be related to the genetic disorder. However, if they appear in the DNA of another family member, it can indicate the person's risk of inheriting the disorder.
- genetic profile:** A collection of information about a person's genes.

genetics:	The field of science that looks at how traits are passed down from one generation to another, through the genes.
genome:	The complete package of genetic material for a living thing, organized in chromosomes. A copy of the genome is found in most cells.
germ cells:	The cells of the body involved in reproduction. Sperm of the male and eggs of the female are formed from germ cells.
germ-line therapy:	The altering of genes in reproductive cells (sperm or egg) in order to affect their function in any offspring that may be created.
heredity:	The handing down of certain traits from parents to their offspring. The process of heredity occurs through the genes.
hormones:	Proteins produced by organs of the body that trigger activity in other locations.
Human Genome Project:	The scientific mission to “read” the order of bases as they appear in the DNA of human chromosomes. The Human Genome Project actually is not one project, but rather many hundreds of separate research projects being conducted throughout the world. The objective is to create a directory of the genes that can be used to answer questions such as what specific genes do and how they work.
Huntington’s disease (HD):	A dominant genetic disorder in which a protein is produced abnormally, leading to the breakdown in the parts of the brain that control movement.
immune disorders:	Health problems caused by the fact that the body cannot properly fight infection.

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- in vitro* fertilization:** The mixing of eggs with sperm in a laboratory dish in order to achieve conception.
- karyotype:** A picture of the chromosomes in a cell that is used to check for abnormalities. A karyotype is created by staining the chromosomes with dye and photographing them through a microscope. The photograph is then cut up and rearranged so that the chromosomes are lined up into corresponding pairs.
- legal issues:** Questions concerning the protections that laws or regulations should provide.
- mutation:** Changes that occur to the order of bases appearing in the DNA inside a cell.
- nucleus:** The central part of a cell where the chromosomes are contained.
- parasites:** Plants or animals that live off another creature (or even inside it), obtaining food and protection without offering any benefit in return.
- paternity:** Identification of the father of a child.
- pigment:** The dyelike material in cells that provides color to skin, eye and hair.
- prenatal:** Before birth.
- privacy:** The condition of being left alone, out of public view and in control of information that is known about you.
- proteins:** The basic chemicals that make up the structure of cells and direct their activities.
- recessive:** Moving back and out of view. In genetics, a recessive gene is a gene that does not express its instructions when paired with a dominant gene.

reproductive technology:	The application of scientific knowledge to assist in making babies.
selective breeding:	The selection of certain seeds or animals for reproduction in order to influence the traits inherited by the next generation.
severe combined immunodeficiency (SCID):	An immune disorder in which the body does not produce the special blood cells that resist infection.
sickle cell anemia:	A recessive genetic disorder in which red blood cells take on an unusual shape, leading to other problems with the blood.
social issues:	Questions concerning how events may affect society as a whole and individuals in society.
species:	A single, distinct class of living creature with features that distinguish it from others.
temperament:	A person's way of responding to the world. Examples of temperament include shy, bold, risk taking, and cautious.
traits:	Ways of looking, thinking, or being. Traits that are genetic are passed down through the genes from parents to offspring.
transgenic:	Containing genes from another species.
ultrasound imaging:	A technique for looking inside the body by using sound waves to create images.
viruses:	Extremely small and simple life-forms, made merely of a protein shell and a genome. A virus reproduces by inserting its genome into the cells of other life-forms. As those cells duplicate, so does the virus.

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