

Introduction

What would you risk to know your future? Would you pay someone to tell you how you'll die? What if there were a test that would tell if you'd ever have cancer. Would you take it? Would you want to know?

Genetic testing seems so exciting. Take a simple blood test to learn how you'll live. But it's not that simple. The tests are rarely perfect. What they tell you may not be what you want to know. Worse still, their results can be abused. People may discriminate against you because of the secrets spelled out in your blood.

It is rare to find an advance in technology that can only be used for good. Genetic testing is no exception. In some hands it improves lives. It helps people have healthy children. It helps doctors provide better treatment. But genetic testing can be used in other ways as well. It can be used to take away people's jobs. It can be used to tell doctors what they can't do instead of what they can.

It is well past time for lawmakers, scientists, and citizens to figure out how genetic testing should be regulated. They must decide together when the use of genetic testing is appropriate, and when it isn't. There must be a way to come to an agreement on how genetic tests should be used, and how they shouldn't. These are the questions that America debates.

Chapter 1: Genetic Testing Defined

Human beings are made by genes. Thousands of them are translated into words of protein, sentences of cells, and paragraphs of organ systems. The language of genes tells the stories that make each of us unique. Each gene makes one protein, one word in the lexicon of life. The way those words are spelled, cut, and combined is the reason your sister has red hair while you have blonde. A thesaurus of possibilities is why your best friend's skin is that beautiful shade of chocolate brown.

What is a gene?

A gene is an instruction.

We read a recipe in a cookbook to learn how to make rice pudding or chicken parmesan. Proteins in our cells read our genes to make more proteins. These proteins become cells, organs, and eventually human beings. What language do cells speak? It's not English or French. It's the language of DNA. It's not a complicated language. The alphabet has only four letters. These four letters, A, C, T, and G, represent the four nucleotides that make up all of DNA. All the words they spell are only three letters long. Although there are 64 words in the language of DNA they only have 22 meanings. They say only "go", "stop", and the names of the 20 amino acids that make up all the proteins known to man.

Just as recipes are made of many words, so are genes. The average size of a human gene is 3000 letters, 1000 words. At least one gene has been discovered that is more than two