

Gus

Honey, Where are my keys?

(He hops on the stage putting on his shoes; early morning rush)
I can't find them any...

Charlotte (offstage)

In your jacket. Where you left them.

Gus

Oh.

(to audience)

It's like this every morning.

(He hops off; Charlotte enters. She is legally blind.)

Charlotte

Gus, we have to talk.

(Gus reenters in his jacket, fixing his tie)

Gus

What now? When you need your glasses to talk it means trouble.

Charlotte

That's right. I want to make sure you're looking at me.

(looking at audience)

Hello, I'm Charlotte. and welcome to the morning Charlotte and Gus
almost came unraveled.

Gus

Uh,... Charlotte, I - I'm gonna be late.

Charlotte

Me too, but this is important. Sit down, Gus. I want to ask you
something. What do you think of Edward Teller?

Gus

Edward Teller....?

Charlotte

The person who was part of the team that developed the Hydrogen bomb.

Gus

I know who he is. I just don't have a whole lot of time to discuss his contributions to science.

Charlotte

I'm not interested in his science. It's his ethics I care about. If you were Edward Teller. And you fully understood the moral implications of the hydrogen bomb. Would you quit your job or would you build the bomb anyway?

Gus

What's this about?

Charlotte

Just answer the question.

Gus

It's a trick question. I'm not building a bomb? I'm building a model for curing diseases. What about the implications of Watson and Crick's work with DNA? Ask me about the ethics of Louis Pasteur! (Directing to her) Or just tell me straight -- What do you want?

Charlotte

I want you to think about quitting your job.

Gus

Quitting.

Charlotte

Yes.

Gus

Well, if I quit at least I wouldn't be late.

Charlotte

You are working the Human Genome Project, and you haven't even begun to consider about the social or ethical implications....

Gus

Don't start Charlotte.

Charlotte

...of your research. Your little laboratory.....

Gus

Don't start.....

Charlotte

.....in it's ivory tower....

Gus

I, I don't need you to tell me the.....

Charlotte

.....will effect people. Real people.

Gus

...implications of my own research.

Charlotte

No. Gus! I do need to tell you. And this time you have to listen!

Gus

What happened? Something happened.

Charlotte

Yes. Just what I told you would happen. I have been arguing all month with the other Vice Presidents in my company. And they just overruled me. They just refused to give life insurance to a man in California who ---- according to some test, which he didn't even know was being performed----- has been told he has a genetic predisposition towards cancer. He doesn't have cancer. He just is more likely to get it than you or me.

Gus

I see. And because your company refused life insurance to this guy, I'm supposed to quit my job.

Charlotte

It is the tip of the iceberg. And, my dear, your laboratory is building the iceberg.

Gus (embarrassed, addresses the audience)

Here, let me explain before you think I am Dr. Frankenstein cooking up some creature in a test tube.

Charlotte

Dissecting a creature and the creature is us.

Gus

She loves to be dramatic. For your information, I am analyzing the chemical sequence of a small gene in a small mouse in the hope of one day replacing that gene with another gene, perhaps a human gene. The implications of this work are enormous.

Charlotte

Yes, enormous! He is a cog in a much larger machine, an international network of scientists funded by the US Government to make a master map of human DNA.

Gus

You make it sound like a cracked brain scheme out of the Third Reich. This is one of the great adventures of our times -- as massive as sending a man to the moon, but with much greater relevance for our life on earth -- by 2010, probably before then--- we will have a complete map of the human genome, all the genes in our bodies -- we'll know the location of each gene on each chromosome. And --- and the code for each gene -- the chemical sequence of the three billion base pairs that make up our genes. We will be on the road to finding the cause of many genetic diseases and common health problems. And the cures. New drugs. Gene Therapy. It's already happening. This is a triumph of human imagination.

Charlotte

Yes it's a triumph. But imagination doesn't exist in a vacuum. Gus, you're such an idealist! Just think how this research can be abused! Take health insurance -- something I know about -- why if we had a child -- a child whose sight was perfectly fine, it might not get insurance, or have to get high-risk insurance, because it has -- not my disease, not my so-called "disability" -- but simply because it has my gene.

Gus

Honey, you know I agree with you. We've got to have a comprehensive public policy about all this. I have no love for insurance companies, but basic research shouldn't stop just because they try to protect their interests.

Charlotte

That's just what my boss says. What does he care if there's a war between my company and my DNA.

Gus

Hey, maybe you should quit, not me. I mean, if you don't like the policies.....

Charlotte

I'm going to change the policies. What are you going to do, Gus?

Gus

I'm going to go to work. Just because there are kinks in our public policy, doesn't mean we stop research.

Charlotte

Public policy? There is no public policy. The public hardly knows there is a Human Genome Project. Why, I bet these people don't even know how much they're spending to pay for this adventure.

(to audience)

How much? Does anyone know how much we're spending in tax money to fund Human Genome research? Three billion dollars. Three billion! And that's just from the Department of Energy. There's even more out there! For what?

Gus

I'll tell you for what. We're trying to understand in a deep and comprehensive way the biological miracle that transforms a tiny egg and a tiny sperm into a thinking, feeling, living human being. It's not just to coordinate the investigation of genetic conditions -- though it will do that! It's not just to develop laboratory techniques for genetic engineering -- though it will do that! It's not just to create economic growth, though it will do that. It's not just to help future research, but it will do that. No! More than that, once we map and sequence every gene in our bodies, for the first time in history, we'll be able to tell -- chemically, physically -- what it is to be human.

Charlotte
(to audience)

That's what I'm afraid of.

Gus

What?

Charlotte
That you are going to tell us what it is to be human.

Gus
Oh. Oh, I see. You think because I'm trying to find ways of inserting new genes in mice, me and my colleagues are sitting around the laboratory concocting a recipe for a perfect human being.

Charlotte
I didn't say that.

Gus
That somehow we are going to find a way to program a super race.....

Charlotte
I didn't say.....

Gus
And create a brave new world of science nerds with perfect teeth.....

Charlotte

Please!

Gus

I hope you didn't say that. My mother's family was wiped out by the master race and I resent the implication that genetic researchers are somehow irrevocably linked to hereditary "cleansing". It like saying ...It's like saying....

Charlotte

It's like saying blind people are crippled.

Gus

Exactly. No!

Charlotte

All I meant was that you and the rest of the scientists working on the Human Genome project haven't really thought through the implications of your research.

Gus

Oh, so we're back to Edward Teller. You think I should be responsible for society's potential misuse of my research? Well, anyway, millions of dollars have been set aside by the Human Genome Project for the study of the ethical, legal and social implications raised by our research. We're all very concerned...

Charlotte

You're a sweet man, Gus, but your mind is in your microscope. It's not enough to be well intentioned. Some of the information you are uncovering will leave people in impossible dilemmas.

Gus

Like what? (to audience) And this is the example she gave me.

Charlotte

Suppose you're like Arlo Guthrie...

Gus

So first I'm Edward Teller, now I'm Arlo Guthrie.

Charlotte

Like Arlo Guthrie. And you know your father....

Gus

Woody Guthrie

Charlotte

Died of Huntington's Disease.

Gus

A progressive, neurological disease that's inherited, and has no cure.

Charlotte

And you've lived all your life wondering whether you are going to start wasting away, deteriorating.

Gus

The condition usually manifests itself in later life.

Charlotte

And you have a 50% chance of inheriting this condition.

Gus

But all your life you've lived with the uncertainty.

Charlotte

Then suddenly there's a genetic test for Huntington's Disease.

Gus

In 1986, a genetic marker for the disease was identified, and recently the gene itself was discovered.

Charlotte

And you now have the chance of finding out with some degree of certainty what your fate may be. What would you do?

Gus

What would you do, she asked me. Well, since 1986, only a small

percentage of the people at risk have requested testing. So we ask you: what would you do? Do you have the test? Or live with the uncertainty?

Charlotte

Would you really want to know if you were, most likely, going to deteriorate like your father did? Or would rather deal with that when and if the time came?

Discussion on testing for genetic conditions
suggested points:

G--pre symptomatic tests might indicate whether you would get a condition like cancer, heart disease, in the future.

C--Before you make the choice, what would you want to know? What should a doctor tell you? Should there be regulations to make sure a person understands the possible implications of genetic testing information? (to a person) What should you know? Do you want to know? And what about accuracy? These tests are not 100% accurate. And they can't tell you the severity or mildness of any condition

Gus

But wait a minute. Wait a minute.. Of course there's going to be problem when you get information like this that you can't do anything about. But I'm sorry, in general, I think knowledge is a good thing. Just one look at how similar we all are genetically across racial lines will throw the lie in the bigot's face. One look at at our own genetic idiosyncrasies should give us more empathy for people with genetic disabilities.

Charlotte

I'm all for knowledge. You know I'm for learning. But how often have knowledge and learning been twisted to terrible purposes?

Gus

Too often. I'm not as naive as you think. But I'm also not afraid to face facts.

(to Charlotte) Look, supposing I had information that your genes showed a tendency towards breast cancer. Wouldn't you want to know that? Wouldn't it be a better inducement to get more mammograms and keep up on examinations? And if you were a smoker, wouldn't that knowledge help you kick the habit?

Charlotte

Yeah, but it also might make me a nervous wreck worrying about a tendency that might or might not affect my life even if I do smoke.

Gus

But at least you'd have an informed choice.

Charlotte

Informed choice. You make it sound like these things simply require rational decisions divorced from any feelings. Gus, you and I both know that there are blood tests out there which might prove that your father isn't really your father. Would you really want to know that?

Gus

Yes, maybe I'm weird. But I would want to know the truth.

Charlotte

Gus, truth can hurt. Truth is a powerful thing. And you're not going to be able to keep your truths in your laboratory, you know that.

Gus (to audience)

So then we got into an argument over the use of truth.

Charlotte (to audience)

Well, why not? Very soon the truth about your genes might be available to almost anyone on a computer print out, in ten years...

Gus

By 2005, maybe less, you will get a printout on a computer, a printout of your genome: where your genes are on each chromosome. The sequence of base pairs that make up our genes. This is not science fiction. The army is already developing the equivalent of a genetic dog tag. They are banking two blood samples of each GI's DNA, so in case the worst happens and the GI gets blown up or something and all that's left is say, some skin -- they can identify the body by the differences in each person's DNA.

Charlotte

But of course that DNA says a lot more than just who you are. It tells the

most intimate information about your inheritance. Your family's tendency perhaps toward Alzheimer's disease, cancer or heart disease. Some even think there's a genetic tendency towards homosexuality, towards alcoholism. So, who would you want to have such information? My insurance company? The FBI? The IRS? The junk mail advertisers?

Gus

Wait, your insurance company deals with statistics. It will want to make policy on the basis of what might happen to you: that's their business. The FBI deals with security risks. They might well think alcoholism is a security risk.

Charlotte

The condition, maybe. But the tendency, the possibility? And what about the IRS? Or the junk mail advertisers? Well, you know it's not going to stop there. Any organization with any clout will get hold of it just like your credit rating.

Gus

Unless there are strict laws. We'll pass strict laws...

Charlotte

See: so idealistic. I think we're going to have genetic ID cards, like social security numbers, and we won't be able to keep anything secret.

Gus

Of course we will. The question is simply one of privacy.

Charlotte

That's what worries me. (to audience) Doesn't it worry you? Who do you think should have access to your personal genetic information?

Discussion: who should have access and how should we protect access?

Points for C - Not only may you lose your insurance, but your whole family could lose it through one person's information

- bring up the idea of the soul

- the environmental factors which contribute to who we are

For G - There is the possibility of treating thousands of conditions which are believed to be genetic

Gus

So we sitting around the breakfast table talking public policy like we're at Bill Clinton's town meeting and I hear myself saying, "I think truth sets you free." And as I say that, it sort of brings me back into the moment and I look at the clock and say, "Honey, I'm feeling a little like I'm in ignorance hell here. Truth time: why are we still staring at our coffee cups and arguing about this? (Pause) And she looks at me with this smile, this Mona Lisa smile, and I know I'm not going to get a straight answer.

Charlotte

You're so naive.

Gus

That's opinion.

Charlotte

Remember our first date?

Gus

Now, that's avoidance.

Charlotte

Our so-called friends fixed me up, cause I was the poor little blind girl who needed a date. So who did they fix me up with? (pause) The nerd.

Gus

(Laughing) Now, that's truth.

Charlotte

They figured: I couldn't see three feet in front of my face and you couldn't get anywhere near a girl without blushing.

Gus

The perfect match.

Charlotte

The perfect match because I'm not just the little blind girl and you are not just a nerd. But our so-called friends didn't know that. They just saw a blind girl and a nerd. And those were our friends. How do you think our

enemies see us?

Gus

What enemies? We don't have enemies.

Charlotte

The point is.....the point is even with the best intentions people put labels on other people. And your genetic mapping is going to make more labels.

Gus

Is that what's worrying you? That we're going to put people like you in a little box marked "genetic defect"? Boy, that is the most simplistic, and unfounded view of my work...

Charlotte

"Like me"? People like me? Just what is like me? Who is "like me"?

Gus

Someone who is blind. For godsake, Charlotte. Someone I love whose genes have made her blind. I've seen how you've struggled. I've seen how you've had to overcome the ignorance and discrimination and sometimes, sheer cruelty of people. And I admire you for it. But I sure as hell am not going to stop working to find a cure. Why do you think I spend my life sticking DNA in rodents? For the love of mice?

Charlotte

A cure?

Gus

Someday....

Charlotte

What if there's nothing wrong with me?

Gus

Oh, Honey, of course there's nothing wrong....

Charlotte

Don't! Don't patronize me. I mean this "scientifically." I've been

thinking a lot about it. If your little mice find a cure for me, Gus, I won't take it. Maybe others in my position would disagree, but I won't take it.

Gus

What do you mean?

Charlotte

I mean I'm not just blind. I am my blindness. My blindness has made me stronger. I never lose things. I always know where I am. Where my things are...the coffee pot, the newspaper, your keys. I'm present, in the moment, here and now. And I keep my focus wide. I notice things.....Things I wouldn't notice if I were always busy looking around. The sound of geese, the bite of snow. My blindness has made me more alive.

Gus

And you don't let anyone push you around. That's what I love about you. And if your blindness is part of all that, then I love your blindness too. But that doesn't mean I quit looking for a cure.

Charlotte

Sweetheart, don't you see: when your mice find a cure for people like me....then people like me may cease to exist. People like me won't choose people like you. And you might never get to know -- no less marry -- someone like me.

(Pause)

Gus

If my mice find a cure, I hope to God it's a cure for suffering, not a cure for differences. I hate your suffering, but I love you. You know Charlotte, when I was in high school I used to have this fantasy that I would find a gene for nerdiness and I would perform surgery on myself, on that horrible piece of nucleic acid that made me such a geek, but then I met you and you were my cure, you're still my cure.

Charlotte

No, No! There's nothing wrong with you! There's nothing wrong with me. We were born perfect. Perfect. Just the way we were meant to be.

(Pause: Gus has a sudden realization.)

Gus

You're pregnant. (Charlotte doesn't answer)
You are. I know you are. Why didn't you tell me?

Charlotte

I - I didn't want...

Gus

A baby! (to audience) a baby! (to baby) Hey, in there!

Charlotte

Shhhhh.

Gus

Hey! What do you think, a boy or a girl?

Charlotte

What do you want?

Gus (laughing)

A little version of you.

Charlotte

Do you, Gus? Do you? Because that's what you might get. A little version of me.

Gus

Oh. Oh. So that's what this is all about.

Charlotte

Maybe. Maybe not.

Gus

I'll call in late for work.

Charlotte

You know...

Gus

I know. There's a 50/50 chance she'll have your eyes.

Charlotte

And you'll love her?

Gus

I already love her.

Charlotte

It's so strange. Even I have it inside me. Deep inside me. I think, even though I know better...even I fear no one will love the little blind girl.

Gus

We will.

Charlotte

Listen to me, sweet. Before you say that. I don't want any form of testing.

Gus

What?

Charlotte

No amniocentesis. No blood tests.

Gus

We'll talk about it.

Charlotte

No.

Gus

We'll talk...

Charlotte

No. I want us to take this baby whatever way she comes.

Gus

What are you afraid of?

Charlotte

I - I don't know. I'm just... I'm just afraid.

Gus (softly singing)

"Hush little baby don't say a word.
Papa's gonna buy you a mocking bird.
If that mocking bird don't sing.
Papa's gonna buy you a diamond ring."

Charlotte

And we held each other and sang to our baby and looked into the future.

Gus

And as we looked into the future, I began to see why she was so upset at her company and at my work.

Charlotte

Of course if a gene inside your baby was going to be fatal then you would probably want to change it. But I guess this is the root of my nightmare. Suppose you could clone a gene for musical ability or mathematics? Suppose you could clone a gene for height, or speed, or beauty? Or at least what we think of as beauty. Would you be tempted? Would we be tempted?

Gus

Well, I know, even though it's silly, if there were a gene for nerdiness, even though I know it's not possible, I wouldn't want my kid to have it. So, are we going to start eliminating categories of people, styles of people?

Charlotte

Where do we draw the line on deciding what is normal?

Gus

What is normal?

Charlotte

And that's the question we left on the table the morning Charlotte and

Gus almost came unraveled.

Gus

And that's the question we'd like to leave on your table as you leave the theatre.

Charlotte

Think of the children...

Gus

This science will change our children, our society...

Charlotte

One way or another, it will change all our lives.

Gus

But we can decide how.

Charlotte

We have to decide how. It's already begun.

Lights out

Both: Thanks for coming....etc.

Mapping the Soul

A play exploring the implications of the Human Genome Project

written by Jon Lipsky for the Museum of Science, Boston

Rewritten Draft 11/97

" Museum of Science/Jon Lipsky

Mapping the Soul is intended to encourage public awareness and discussion of the potential benefits and the ethical, legal and social implications of the Human Genome Project. Funding for this project was provided by an educational grant from the New England Regional Genetics Group (NERGG). The information and views presented in the play are not intended to represent those of the NERGG, or those organizations or individuals involved in the development.

Principal investigators: Robin Blatt and Michael Alexander

Genome Advisory Committee

Betsy Anderson
Federation for Children with Special Needs

Carol Barash, Ph. D.
Shriver Center

Hope Charkins, M.S.W.
Treacher Collins Foundation

Allen E. Crocker, M.D.
The Children's Hospital

Paula K. Haddow
Foundation for Blood Research

Marsha Lanes
Prenatal Diagnostic Center

Marvin Natowicz, M.D., Ph. D.
Shriver Center

Ruth Ricker
U S Department of Education

Joseph Robinson
New England Regional Genetics Group

Jamie Stephenson
New England Fragile X Parent Resource Center

Sue Stafford, Ph. D.
Simmons College

Dorothy C. Wertz, Ph. D.

Shriver Center

Nachama Wilker
Council for Responsible Genetics

Betsy Wilson
Let's Face It

Comments from evaluation questionnaire of Mapping the Soul

What might be a positive impact of the Human Genome project?

"Lessening the frequency of Spina Bifida, other awful, torturous diseases"

"Targeting disease and developing cures/treatments"

"We may be able to effectively treat diseases like Alzheimers and Cancers if we better understand a person gene makeup. I point to the valuable work of companies doing enzyme replacement work as a direct benefit of this work."

"- most important to establish public policy

- potential to save lives"

"Ability to test for a predisposition for a genetic condition"

"The more knowledge we would have of human beings should be used to help them have healthier longer lives"

What might be a negative impact of the Human Genome project?

"A society could become very brutal because there is no real chance for human beings to see the borders. There should be limits for the sciences."

"Discrimination"

"Public policy must be carefully established"

"define 'normal' in one group's seems, and possibly lead to a so called 'Master-race' versus the 'proletariat'."

"People love to test and measure themselves, therefore they will want to compare their DNA against what scientists determine as 'normal'."

"It might be used to encourage abortions of fetuses with what might be considered defects"

In what way, if any, did the play affect your opinion of the Human Genome Project?

"more public discussion on the use of that information should be promoted."

"It has given me information to develop opinions on."

"made me think about it for the first time and how it could really affect our lives beyond scientific controversy."

"As I am studying Biochemistry myself, I am very critical about the aims of science. I think that too much research has been done all ready."

"made me more aware of both sides of coin by raising questions."

"The woman thinks she is being rational, as many of her views will be, [be] she is not. She is emotional and it is hard to talk with those like her. I can better understand this now."

"Reinforced my favorable impression of the project."

"As a MD, never thought much about the social implication (negative)"

"It raised my awareness. I have studied this in relationship to environmental law, but didn't realize how little I had been thinking about the impacts."

"It made me think, once again, about the fact that every act of discovery is also an invasive act of destruction, despite whatever positive results also ensue."

Please comment on the use of theater as a way to present scientific issues...

"I would not have the information and thoughts about this project without it."

"It's great, it made it real."

"great - with good balance of Humanness of Issue as well."

"I liked it. Shows people to learn thru a way they are not used too. This was excellent!"

"skits like this one, on ethics, are very badly needed to get people to consider implications."

"I enjoyed the play very much especially the endorsement of the

audience (people feel more affected)"

"Excellent method, provided the audience is knowledgeable."

"I think it is most important to talk about it."

PAGE

PAGE 1