

## Appendix A: Community Conversations

- Ethics Cases for Generating Discussion
  - Flyer for “Am I My Genes? Race, Genes, and Ancestry in Today’s World”
  - Flyer, Spanish Translation, “Your Genes and Your Health”
  - Invitation to Forum Session Leader
  - Notetaker Guidelines
  - Discussion Guidelines
  - Next Steps Board Comments
-

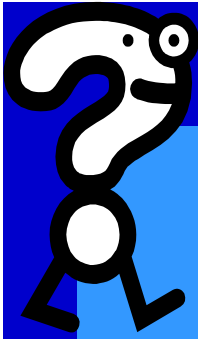
## Case Ethics Cases SMEP

Many people are interested in learning more about their family history, and in tracing their family trees. Recently, ancestry testing has also become popular. For ancestry testing, people provide DNA specimens to organizations and companies that try to match individuals' DNA profiles to DNA specimens from people in different parts of the world. The test results are described to people as suggesting where your ancestors may have come from.

Let me give you an example to start our discussion.

James is adopted. He grew up in the Triangle in a middle-class family; his father is Irish and his mother is Italian. He has a sister, Maria, who was not adopted.

1. When James turns 16, he says to his parents, "I'd like to try to find my real parents." What do you think he means by 'real'? Who do you think his real parents are?
  2. When James turns 16, and he and his parents start thinking about college, James' father and mother ask him to provide a DNA sample to an ancestry testing organization. They know little about his biological parents, but have always wondered about his features. James' ancestry report comes back describing him as having 20% "possible Native American" ancestry and 30% "possible West African" ancestry. James' parents think that James should apply for minority scholarships to college. What do you think?
  3. James and Maria, now ages 20 and 19, end up attending the same university. Both of them are bookworms like their parents, and prefer video games to hitting the gym, so both are a little overweight and have never been in shape. At Student Health, James sees a recruitment ad for a research study. The study will collect blood for DNA testing, and look for genes that might be associated with adult-onset (type II) diabetes and with high blood pressure. The study wants to enroll as many students as possible, especially racial and ethnic minorities. Race and ethnicity are recorded as "self-report" – that is, whatever the research subject says. How should James describe himself?
  4. Both diabetes and high blood pressure are more common in African-Americans than in white Americans. Diabetes is also more common in Native Americans. Diabetes and high blood pressure are also known to be associated with being overweight, being inactive, and eating a diet high in salt and fatty foods. Do you think that James should worry more than Maria about developing these diseases? Do you think that James is more likely than Maria to have some genes that are associated with these diseases?
-



Ideas! Coffee House &  
Finding the Genome:  
Community Genetics Forum 2006  
present a community conversation

"Am I My Genes?"  
Race, Genes, and Ancestry in  
Today's World

Come participate in a community conversation about genetics, ethics, race and ancestry in our society. Conversation will address issues like "if race is not genetic, why is race used in genetics?" and "what can ancestry testing tell us— what can't it tell us?" All community members are welcome and encouraged to share their thoughts, opinions and concerns. Please contact Ideas! Coffee House for more Information at 919-405-4140 or visit [www.ideascoffeehouse.com](http://www.ideascoffeehouse.com)

Saturday July  
1st  
12:00 - 1:30  
Ideas Coffee  
House  
2105 E. NC  
Highway 54

Visit <http://genomics.unc.edu/cgf/> for other events and more information about the Community Genetics Forum 2006

## Encontrando el Genoma:

Friday, August 25th  
10:00 am — 11:30 am  
Holy Family Catholic Church  
216 Governor Burke Road (Off Hwy 57)  
Hillsborough, NC



### "Sus Genes y Su Salud"

Cada día las noticias anuncian el descubrimiento de un gene relacionado a una enfermedad común como la diabetes y las enfermedades del corazón.

Venga y participe en una conversación acerca de asuntos en genética, ética, genes y salud que afectan nuestra comunidad.

La conversación considerará preguntas como:  
¿Qué podemos aprender de las pruebas genéticas, acerca de nosotros y de nuestra salud? ¿Nos ayudarán estos descubrimientos a estar más saludables? ¿Cómo afectará esto el acceso al cuidado de la salud? ¿Cómo afectará esto los seguros de salud y los costos del cuidado de la salud?

Todos los miembros de la comunidad son bienvenidos y alentados a compartir sus pensamientos, opiniones y preocupaciones. Por favor llame al 919 843 6876 para mas información.

El Foro de la Comunidad sobre Genética 2006 está patrocinado por el Instituto Nacional de Investigación del Genoma, el Instituto Nacional de Salud, el Centro Carolina para la Ciencia del Genoma, la Escuela de Medicina de UNC, El Instituto para la Ciencia y las Políticas sobre el Genoma de Duke, Medicina de Duke y el Centro Parr para la Ética. Para más información sobre estos eventos, vaya a: <http://genomics.unc.edu/cgf> (en inglés)

Dear [            ],

We write to ask your participation in one of two day-long conferences on Friday, September 15, and Saturday, September 16, 2006. Specifically, we would like you to co-lead a concurrent breakout session during the Saturday, September 16 afternoon conference day. These concurrent sessions are core components of the conference days. Both conferences are part of a series of National Human Genome Research Institute-sponsored community outreach and education events, "Finding the Genome: Community Genetics Forum 2006," and are described further below.

UNC's Planning Center for Excellence in ELSI Research is sponsoring this year's Community Genetics Forum, in collaboration with NHGRI, the Durham County Library, the Carolina Center for Genome Sciences, the Parr Center for Ethics, and Duke University's Institute for Genome Sciences & Policy and Center for the Study of Medical Ethics and Humanities. The focus of the Community Genetics Forum is genetic research and testing. The conferences are the culmination of a wide variety of events and activities undertaken throughout the year in the Triangle area. Other activities are outlined in the attached brief project description and on our web-site: [genomics.unc.edu/cgf/](http://genomics.unc.edu/cgf/).

The Colloquium scheduled for Friday, September 15, focuses on group interests in genetic research and will be held in the MBRB Main Auditorium on the Health Affairs campus of UNC. Materials for this day are geared toward a general scholarly audience, drawing on faculty and students from UNC, Duke, NCSU, and NCCU, as well as the interested general public. The Public Forum scheduled for Saturday, September 16, will be held at the North Carolina School of Science and Math in Durham, and is intended for a community-oriented general interest audience of all ages from around the Triangle area and elsewhere in the state. Preliminary schedules for both days are attached.

On both conference days, plenary talks by Dr. Francis Collins of NHGRI, Dena Davis, PhD, JD, Professor at Cleveland-Marshall College of Law, and Debra Harry of the Indigenous Peoples Council on Biocolonialism will be followed by a selection of small, interactive concurrent seminar sessions on a range of topics and issues relating to genetic research and testing. These topics relate both to the plenary speakers' talks and to the issues and interests identified in community conversations and consultations during the spring and summer of this year.

Each concurrent session is intended both to provide information and to provoke discussion. Each will be co-led by two scholars, whose principal expertise lies in genetic science and medicine and/or in addressing the ethical, legal, and/or social implications of genetics. Other area scholars, plenary speakers, and staff scholars from NHGRI will also attend a number of the sessions and may be available to help guide discussion at the discretion of the co-leaders.

We would like you to co-lead the following session as a part of the FRIDAY / SATURDAY colloquium: (please note that we are gathering community input for the Saturday discussions and a full description of the session will be provided in the near future)

INSERT APPROPRIATE SESSION DESCRIPTION

---

We hope this session description is general enough to cover any particular focus that you and your co-leader may want to emphasize. However, if you think that a different session description would more closely reflect a topic of interest to you, please send us the proposed description.

All concurrent sessions will take place in the early afternoon on both conference days, and last 60-90 minutes. We will provide you with some session materials. We will also put you in touch with your co-leader as soon as he or she responds to our invitation.

We are delighted to be able to showcase the wealth of expertise among our colleagues in the realm of genetic research and its implications. With your invaluable and much-appreciated help, we will be able to shape a memorable Community Genetics Forum conference. Likewise, we hope that you will find value in participating.

We ask that you respond to our invitation by contacting Nancy King, Rebecca Walker, Barbra Rothschild, or our project coordinator, Kristin Meyer, as soon as possible, but by July 15 at the latest. Our complete contact information is below. Please feel free to call or email us with any questions you might have as well. In the event that you are not able to participate, we will need time to ask other area scholars about their availability.

Once we have assembled a range of concurrent sessions, their descriptions will be posted on the web for each conference day. We will ask participants for each conference to pre-register and indicate several choices of concurrent sessions so that we can track likely session attendance. If registration preferences indicate that a particular session is likely to be heavily or lightly attended, we may need to modify the offerings. If your session is affected by these modifications, we will confer with you about how to best to both make use of your contributions and accommodate conference participants' interests.

Attachments: One page project description, conference schedules

Sincerely,

Nancy M. P. King, [nmpking@med.unc.edu](mailto:nmpking@med.unc.edu), 843-8270

Rebecca Walker, [rlwalker@med.unc.edu](mailto:rlwalker@med.unc.edu), 843-6896

Barbra Rothschild, [rothschild@unc.edu](mailto:rothschild@unc.edu), 966-3024

Kristin Meyer, [kristin\\_meyer@med.unc.edu](mailto:kristin_meyer@med.unc.edu), 966-3024

---

***The Human Genome and Being Human:  
A Community Conversation on our DNA, Health, Values and Heritage***  
**September 16, 2006**  
**North Carolina School of Science and Math**  
**Durham, North Carolina**

**Guidelines for Notetaking on Breakout Sessions**

**ROLE:** First, many thanks for agreeing to take notes during the breakout sessions. We are hoping to capture enough of the conversation that takes place during the sessions to have a good record of how the session went, what ideas and concerns participants expressed as well as what questions they posed during the session. You will be our eyes and ears.

**PROCESS:** We ask you to take notes by hand and type them up later. Notepads will be provided. We expect the groups to be fairly small and laptops, especially in small groups, can feel intrusive. If at all possible, and so your general impressions of the session aren't lost through the passage of time, we would like to receive your typed notes by the end of next week, **Friday, September 22. Please email them to Nikki Vangsnæs at: vangsn001@mc.duke.edu**

**THE NOTES:** We would like to have as much consistent information about the sessions as we can get, but don't expect you to write a verbatim transcript of what happened. Please record what you can, using the categories below.

**Description of Session Content**

Briefly describe (about one paragraph) the material covered by the presenter.

**Characteristics of Group**

Number in the session

Gender of participants

Other characteristics you deem notable

**Views Expressed/ Questions Asked**

We don't need a description of who expressed what views but we would like to have a record of the diversity of views, whether there was group endorsement of any particular views, and what topics engendered agreement or disagreement. Please try to record all the questions asked.

**Group Dynamics**

Please record your observations about the group process: did all get a chance to express their views, did someone dominate the conversation, and did people listen to each other? What was the overall mood of the group? Did it shift during the course of the conversation and why?

**Finally,** please introduce yourself to the session presenter at the beginning of the session and let him/her know you are the person who has been asked by the forum planners to take notes. FYI, presenters will be leaving 5-10 minutes at the end of the session to do a wrap-up which they will record on poster paper. Presenters will be handing in notes from the wrap-up, so you do not need to also record what the presenter writes down.

---

## Discussion Guidelines for Concurrent Session Leaders

Concurrent sessions are intended to be more like seminars than lectures. Time is relatively short, and leaders may therefore feel the need to impart a lot of information quickly. However, these small groups are also a principal opportunity for audience to voice their own views and engage with others at the conference. Therefore, our goal is informal exchange, and we ask that session leaders serve as facilitators rather than solely as experts.

Attendees for each concurrent session will receive one or two relevant short readings as handouts, either at the beginning of the conference or in each session. You are free to bring additional materials for your group if you wish.

If at all possible, talk with your session co-leader beforehand – ideally, before the day of the conference, but if not, talk over lunch and plan your session.

Introduce yourselves and, if possible considering the number of attendees, go around the room and ask everyone for a brief introduction. If the group is too big to do that easily, ask speakers to give their names and affiliations when they make a (first) comment.

Lay session ground rules, such as, “I know we only have an hour or so, so we’re going to try to be sure that everyone gets a chance to engage in discussion.”

Start with a few points or issues relating to the session topic that you want to make. Try to connect them to the morning plenary, so the group can see the session as taking a topic that is already on the table and pursuing it in more depth. Putting your points in the form of questions to the group can help promote discussion. Identifying disagreements or differences in perspective between the discussion leaders can also help to break the ice.

Plan to simply let things flow, but be ready to keep a list of people who wish to speak, and call on them in order, if discussion gets very busy.

If there are attendees who seem to dominate, call on others first, explaining: We want to hear from as many people as possible, so we’ll come back later to those who have already spoken.

Do not be drawn into one-on-one arguments/discussions with attendees. Instead, use your role as discussion leader to demonstrate to the group how viewpoints are built on facts, experiences, principles, values, and reasoning.

Think in advance about what you might do if you find yourself needing to foster exchanges rather than pronouncements. Use tools like: [to an individual] Can you say more about that? Can you tell us a little about why you think that? [to the group] Are there other possible views that anyone can think of? How do these views compare? “What if X were true?” questions that change the example can also help.

When you are asked questions, try not to answer simply from your expertise, or from your own opinions; provide information, provide some context for the information and use your answer to open up a new question or issue for the group. This will help move discussion from expert Q&A to group exchange.

---



If there is a lot of interest in your expertise from some of the group, invite them to talk with you further after the concurrent session, and/or offer to provide them with references or other follow-up as appropriate, so that group discussion can proceed in other directions during the session. (If everybody says, “No, no, keep talking!” then just go ahead and keep talking.)

Let the group know that one goal of the concurrent sessions is to bring some points and questions back to the closing session of the conference. Ask someone to take notes, and take a minute or two at the end of the session to summarize the discussion and ask the group what they think are the main points to raise in closing. (There will not be a formal reporting-from-the-sessions at the end on either conference day, but this will facilitate the closing sessions on both days.)

Please end on time, and thank everyone for their contributions to discussion.

(As we thank you for yours.)

---

**Next Steps Board**

September 16, 2006

Notetaker: Nancy King

These are the comments of the community participants in the Next Steps Board at the Community Genetics Forum 2006:

- How can we make sure that genetic scientists and people of faith talk together?
  - Scientists should help non-scientists understand genetics
  - Bioinformatics
  - We need to remember that the human body is complex and there is still so much we don't know. Genes aren't everything.
  - We need better ways to understand the environment's effects on individuals' health and disease.
  - I've seen 2 phylogeny maps in National Geographic showing inferred relationships between different species based on gene sequences. Are there more such evolutionary-genetic maps posted on the Internet?
  - Why is HR 1227 stuck in committee?
  - Science, society, culture, law, religion – it is all intertwined. We cannot analyze one without considering the others.
  - What happens when we can 'fix' disabled people before birth? How much do we fix – obesity? heart disease? balding? blue eyes?
  - Dr. Collins – Please tell how you came to write your recent book *The Language of God*. Tell about your 180-degree change of mind.
  - "The only race we're talking about is the human race." —By the way, how's Darth Venter?
  - What do you see in the future for gene therapy in regard to treating neurological diseases such as ALS, schizophrenia, Alzheimers, etc.? What would you suggest for a person interested in doing research in genomics? How does one go about getting into the field?
  - Do a session with Bonham on race and DNA and lacrosse.
  - What does it mean to YOU to be 98% chimpanzee?
  - Let's not forget that disabled people are not "broken" human beings – each one is perfectly himself or herself.
  - How do we get better public awareness of pending legislation on health care coverage and genetics policy issues? (Is media a failure due to bias?)
  - We need to address the issues of class, the availability of medical care, and the excessive costs of the new therapies and services that the genomics revolution has brought and will bring
-

to the world. (ps, if Dr. collins ever needs his guitar fixed, he should look up Curbow stringed instruments.)

- Today really encourages us to follow our interests in genomics, whether it be scientific research, public policy, or ethics. Duke/UNC have provided us with great resources and opportunities. Thank you! —Duke Genome Revolution Focus Class 2010
- Audience comment: Don't forget the arts!



## Appendix B: Finding the Genome Conference

- Participant Welcome Letter
  - Poster
  - Flyer
  - Flyer
  - Agenda for Thursday
  - Agenda for Friday
  - Agenda for Saturday
-

Dear NHGRI Participant,

Welcome!

Thank you for joining us for the Community Genetics Forum 2006. We appreciate the time and effort you are making to engage North Carolina in a conversation about genetics and we hope your time here is stimulating and worthwhile! We are a diverse community grounded in tradition but with a history of progressive action.

Many of the events on Friday take place at the Microbiology Research Building (MRB) home of the Carolina Center for Genome Sciences. UNC established the Carolina Center for Genome Sciences (CCGS) in August of 2001 with faculty appointments from 7 different academic units representing over 15 departments and disciplines. The Center has also invested significantly in state-of-the-art laboratories and core facilities, which are critical for making progress in this technology-driven endeavor. Furthermore, the CCGS is committed to training the next generation of basic scientists and clinicians in the genome sciences. To this end, several training programs have been established representing a variety of disciplines such as plant genomics, computational biology, and medical genetics. CCGS encompasses an impressive array of faculty members, facilities, training programs and outreach efforts. UNC-Chapel Hill is dedicated to making significant advances in basic genomic research, as well as translating these discoveries to improving healthcare, education and society.

You will notice that many of our faculty come from the UNC Department of Social Medicine. The Department of Social Medicine was created in 1978 as a new academic unit to incorporate the long-standing interest of the University of North Carolina School of Medicine in community medicine and health care delivery systems. The mission of the Department of Social Medicine is to inform the work and thought of physicians on: (1) the social conditions and characteristics of patients, the social causes of illness and the social barriers to effective care; and (2) the social responsibilities of the medical professional. The Department carries out its mission through a variety of educational, research and service activities in several venues and almost always in interdisciplinary collaboration throughout the Chapel Hill campus.

We also want to thank our partners for their unending support for this year-long endeavor: The Parr Center for Ethics at the University of North Carolina, Duke University Center for the Study of Medical Ethics and Humanities, Duke University Institute for Genetic Science and Policy, Durham Public Library, and The North Carolina School of Science and Mathematics.

In this packet you will find:

1. A schedule of events.
2. Maps and directions to various events and to the airport.
3. Short biographies of event speakers and selected participants.
4. Background reading material
5. Information on the Carolina Center for Genome Sciences

If you have questions while you are here, please feel free to contact me at 919-622-2142 at any time.

Many thanks,

Barbra Rothschild  
Assistant Professor  
Department of Social Medicine

Terry Magnuson  
Sarah Graham Kenan Professor  
Chair, Department of Genetics

---

# FINDING THE GENOME

*RfdFiskal lEdn dcl b@cg eFiskal:8  
?Ank k sl gyAnht cpq rgh lnh lMspB lA?,\*  
Flajnf,\*Tajscqal bFl cpq ec*

SATURDAY, SEPTEMBER 16TH  
10:00 AM – 3:00 PM

THE NORTH CAROLINA SCHOOL  
OF SCIENCE AND MATHEMATICS  
DURHAM, NC

## COMMUNITY GENETICS FORUM



### SPONSORED BY

Resrep, yqer Kirsqi i/weg Mwnxi R exsrep  
Mwnxi vj l i epl Kl i Yrzi wj Sj Rsvl S exspre  
exl et i p m Hoi Yrzi wj Kl i Rsvl S exspre  
Vj sspj Sjirg r h Q el i q exg l

Jim Spence, Director of the  
National Human Genome Research  
Institute, Spence, and Spence  
Happ on an exciting and engaging event  
that brings together community leaders  
experts in the field and community  
members

Many hopes and questions may arise  
with genetic testing advances in the  
field of genetics. Come share your  
opinions and learn the facts!

Our three speakers will present on the  
morning followed by a question and  
answer session with a community panel.  
After lunch, please join us for break-out  
sessions on topics such as: DNA and  
Your Health, Ancestry Testing and  
Privacy and DNA. There will be a  
workshop by the Linx Permenence  
Exchange and a DNA Extraction  
Demonstration for adults and children.

For more information and to register for this free colloquium  
please visit <http://genomics.nc.edu/egfb>  
NCWM 5525 Broad Street, Durham, NC 27709

Registration is free

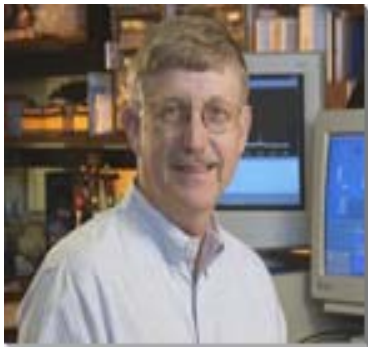


## Finding the Genome

# A Two-Day Special Event

University of North Carolina at Chapel Hill

This forum is open to the public and a special program has been designed for undergraduate students interested in pursuing a career in science, health, or medicine.



Dr. Francis Collins—  
Director, National Human Genome  
Research Institute (NHGRI)

### Thursday September 14, 2006

- ##Meet current UNC graduate students and postdoctoral fellows at a dinner social
- ##Interact with special guests from the NHGRI

### Friday September 15, 2006

- ##Meet and interact with Dr. Francis Collins
- ##Learn about ethical and social issues surrounding the Human Genome Project from experts at NHGRI
- ##Tour research laboratories at UNC Chapel Hill
- ##Learn about careers in genomic sciences and medicine

Please visit <http://genomics.unc.edu/cgf/> to register and to view a full program description. Registration is **required**. Overnight accommodations are provided for those students who request a room on the registration page.

This event is sponsored by UNC Chapel Hill's SPIRE Postdoctoral Fellowship Program, members of the Partnership for Minority Advancement in the Biomolecular Sciences (PMABS), the National Human Genome Research Institute (NHGRI), and UNC Chapel Hill.

## Finding the Genome:

Saturday, September 16th

10:00 am — 3:00 pm

The North Carolina School for

Science and Math

Durham, NC



### The Human Genome and Being Human: A Community Conversation on our DNA, Health, Values and Heritage

Join **Dr. Francis Collins, Director of the National Human Genome Research Institute**, Dena Davis and Debra Harry in an exciting and engaging event that brings together community leaders, experts in the field and community members who are interested in learning and sharing about advancements in genetic technology.

Genetic science affects our lives in numerous ways. Many hopes and questions may arise with recent exciting advancements in the field. Come share your opinions and learn the facts!

Our three speakers will present in the morning. Breakout sessions on various topics and a town hall style community panel with question and answer session will complete the day. Lunch will be served.

For more information and to register for the colloquium, please visit <http://genomics.unc.edu/cgf/> or contact Kristin Meyer at 919-966-3024

• National Human Genome Research Institute • University of North Carolina at Chapel Hill • Duke University • Carolina Center for Genome Sciences • Parr Center for Ethics • The North Carolina School for Science and Math •



**Finding the Genome: Community Genetics Forum 2006**

Thursday, September 14

***Nursing in the Genomic Era & the Importance of Family History***

Location: Friday Center, Chapel Hill, NC and School of Nursing, UNC at Chapel Hill

Time: 9:00 am – 4:30 pm

NHGRI participants: Jean Jenkins, Dale Lea

9:00 am Nursing Continuing Education Conference open to area Nurses

1:00-1:15 Welcome and Overview of Program  
Marcia Van Riper, RN, PhD  
Faculty, UNC School of Nursing

1:15-2:15 Essential Core Competencies in Genetics for All Nurses  
Jean Jenkins, RN, PhD, FAAN  
Senior Clinical Advisor, Office of the Director, NHGRI

2:30-3:30 The U.S. Surgeon General's Family History Initiative  
Dale Halsey Lea, RN, MPH, CGC, FAAN  
Health Educator, NHGRI

3:30-4:15 Integrating Genetics into Your Practice  
Marcia Van Riper, RN, PhD

4:15-4:30 Summary and Evaluation

***Community Genetics Forum: Policy Roundtable***

Location: Institute of Arts and Humanities, Hyde Hall, UNC at Chapel Hill

Time: 5:00 pm -7:30 pm

NHGRI Participants: Francis Collins, Alan Guttmacher, Laura Rodriguez, Phyllis Frosst, MK  
Holohan, Vence Bonham, Elizabeth Thomson

5:00-5:30 Hors D'oeuvres, Meet and Greet

5:30-5:40 Introductory Remarks by Dean William Roper,  
Dean, School of Medicine UNC at Chapel Hill  
(Dinner)

5:40-5:55 Introductory Remarks by Dr. Francis Collins, Director, NHGRI

5:55-7:00 Roundtable Discussion on Genetics Policy Issues in North Carolina

---

***HBCU students and Area Undergraduates Welcoming Program***

Location: Friday Center, Chapel Hill, NC

Time: 6:00 pm -9:00 pm

NHGRI Participants: Carla Easter, Milton English, Sarah Harding

6:00-7:00 Pizza Dinner with Graduate Students and Medical Students

7:00-9:00 Opportunities in Genetics at NHGRI  
Carla Easter, Science Education Specialist, NHGRI  
Sarah Harding, Community Outreach Analyst, NHGRI  
Milton English, Post-Doc, NHGRI



Friday, September 15

**Breakfast**

**sponsored by Department of Social Medicine and Initiative for Maximizing Student Diversity**

Location: TBD  
 Time: 7:30 am -8:45 am  
 NHGRI Participants: Vence Bonham, Milton English, Carla Easter, Laura Rodriguez, Francis Collins

***Finding the Genome: Group Interests in Genetic Research and Testing***

Location: MBRB Main Auditorium, Health Affairs Campus, UNC-Chapel Hill  
 Time: 9:00 am -3:00 pm  
 NHGRI Participants: Francis Collins, Alan Guttmacher, Vence Bonham, Sarah Harding, Laura Rodriguez, Eric Green, Elizabeth Thompson, Phyllis Frosst, Dale Lea, Jean Jenkins, Vivian Ota Wang, Rebecca Kolberg, Les Biesecker, Carla Easter

9 AM Welcome and Introductions by Dean Roper

9:20 AM Plenary Lecture: Francis Collins, MD, PhD , Director NHGRI

10 AM Plenary Lecture: Debra Harry, Executive Director, Indigenous Peoples Council on Biocolonialism

10:40 AM Plenary Lecture: Dena Davis, PhD, JD, Professor of Law, Cleveland-Marshall College of Law

11:15 AM Panel Q&A/Discussion with Speakers, Moderated by Jim Evans, MD PhD

12:00 PM Lunch (pick up box lunches)

12:45 PM Concurrent Breakout Sessions:

- But Race Isn't Genetic, Is It? – Vivian Ota Wang, Giselle Corbie-Smith
- Genetic Narratives, Group Narratives, and the Media Rebecca Kolberg, Felicia Mebane, Joseph Jordan
- Health Disparities, Genetics, and the Rhetoric of Responsibility – Gail Henderson, Jay Kaufman, Elizabeth Thomson
- Groups, Genetics, and Research Oversight – Laura Rodriguez, Nancy King, Lynn Dressler
- Genes, Family, and Ancestry – Les Biesecker, Karla Holloway
- Genetics and Behavior – Jessica Nadler, Amy Laura Hall
- Genetics and Clinical Translation: Eric Green, Chuck Perou, Howard McLeod

2:15 PM Reaction Panel and Wrap-up Discussion with Plenary Speakers, Francis Collins, Dena Davis, and Debra Harry, moderated by Jim Evans, MD, PhD including Adam Searing, Diane Baker, Karla Holloway, and Terry Magnuson

---

**Additional Activities for Undergraduates, Graduate Students and Post-Docs**

- 12:00-1:00 Francis Collins, The Future of Genomic Science  
Location: Lineberger Cancer Center  
Participants: Graduate Students and Post-Docs
- 3:00-4:00 Francis Collins, The Future of Genomic Science  
Location: MBRB Small Auditorium  
Participants: HBCU visitors and Undergraduates
- 3:00-4:30 NHGRI Expert Panel  
Overview of Basic Research and career options – Eric Green  
Overview of Clinical Research and career options – Les Biesecker  
Overview of ELSI and career options - Elizabeth Thompson  
Overview of Science Policy and career options – Laura Rodriguez,  
Phyllis Frosst  
Overview of Education and Outreach and career options – Carla Easter,  
Dale Lea, Jean Jenkins  
Questions and Answers - ALL (20 minutes)
- 4:30-6:00 Expert Panel Reception with Graduate Students, Post-Docs and  
Undergraduates
-

**Saturday, September 16**

***The Human Genome and Being Human:  
A Community Conversation on our DNA, Health, Values and Heritage***

Location: North Carolina School of Science and Mathematics,  
300-400 participants anticipated

Time: 10:00 am -3:00 pm

NHGRI participants: Francis Collins, Alan Guttmacher, Vence Bonham, Sarah Harding, Laura Rodriguez, Eric Green, Elizabeth Thompson, Phyllis Frosst, Dale Lea, Jean Jenkins, Vivian Ota Wang, Rebecca Kolberg, Les Biesecker, Carla Easter

- 10:00 Welcome and Introduction by Representative David Price
- 10:10 Brief Lectures by Francis Collins, MD, PhD , Director, NHGRI; Debra Harry, Executive Director, Indigenous Peoples Council on Biocolonialism; and Dena Davis, PhD, JD, Professor of Law, Cleveland-Marshall College of Law
- 11:10 Panel and Town Hall Meeting featuring Plenary Speakers, Reverend Harry Edmonds, Omisade Burney-Scott, and Holly Riddle moderated by Jim Evans, MD, PhD
- 12:00 Lunch (pick up box lunches)
- 1:00 Concurrent Breakout Sessions:
- Ancestry Testing: Understanding our Heritage through DNA - Vivian Ota Wang, Karla Holloway, Joseph Jordan
  - DNA & Health: The Role of Biomedical Research – Alan Guttmacher, Giselle Corbie-Smith, Elizabeth Thompson
  - Genetic Enhancement & Designer Babies: Can we, should we? Arlene Davis, Muge Calikoglu
  - Privacy & DNA: Who should and can know your private DNA information? Phyllis Frosst, Lauren Dame
  - Genetics, Behavior, & Ethics: What do genes have to do with your personality? – Bob Cook-Deegan, Amy Laura Hall, Jessica Nadler
  - Genetics, Heart Disease, Diabetes, and Cancer - Karen Mohlke, Dale Lea, Jean Jenkins
  - The Liz Lerman Dance Exchange Workshop
  - Forensics and DNA– Les Biesecker, Ben Gilbert
  - What’s New and Exciting in Genomics Research!?!? (for NCSSM students) – Eric Green, Jim Evans
  - DNA Extraction! For Kids and Adults alike! – Amanda Nave, Carla Easter
- 3:00 Wrap up Session
-

## Appendix C: Finding the Genome Film Series

- Poster
  - Booklet
  - Bookmark
  - Discussion Guide
  - Curtain Speech for Guest Facilitators
  - Handout for Further Reading
  - Gattaca Film Flyer
-

# FINDING the genome

## Fact & Fantasy

A film series that explores the moral questions, dilemmas, and controversies about scientific advances in genetics.

### FRANKENSTEIN

(1931, 71min, unrated)

March 11 (Double Header)

2 p.m.

Main Library, 300 N. Roxboro St.

### LILO AND STICH

(2002, 85min, PG)

March 11 (Double Header)

2 p.m.

Main Library, 300 N. Roxboro St.

### TOMORROW'S CHILDREN

(1934, 70min, unrated)

April 1

2 p.m.

Main Library, 300 N. Roxboro St.

### THE MADNESS OF KING GEORGE

(1994, 107min, PG-13)

May 13

2 p.m.

Southwest Branch Library,  
3605 Shannon Rd.

### X-MEN

(2000, 104min, PG-13)

June 10 (Teen Summer Reading Kick-Off)

2 p.m.

Main Library, 300 N. Roxboro St.

### MINORITY REPORT

(2002, 145min, PG-13)

July 8

2 p.m.

East Regional Library,  
211 Lick Creek Lane

### MOTHERLAND: A GENETIC JOURNEY

(2003, 89min, unrated)

August 12

2 p.m.

Stanford L. Warren Library,  
1201 Fayetteville St.

### GATTACA

(1997, 101min, PG-13)

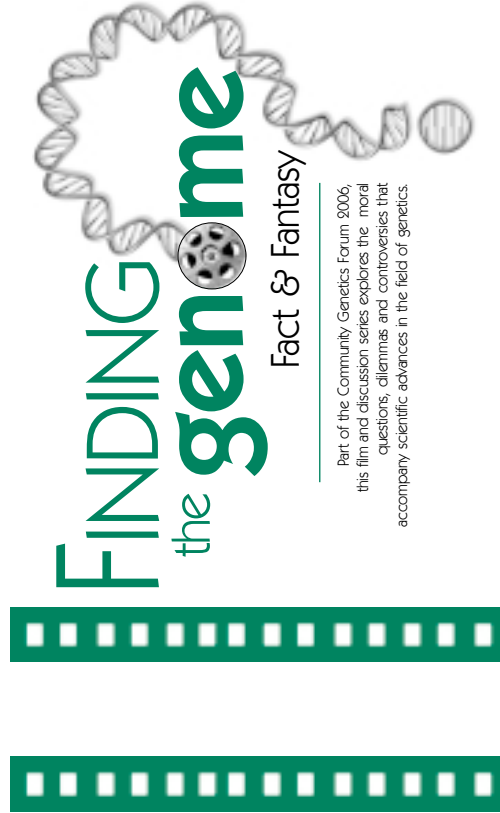
September 9

2 p.m.

Main Library, 300 N. Roxboro St.



THE UNIVERSITY  
of NORTH CAROLINA  
at CHAPEL HILL



# FINDING the genome

Fact & Fantasy

Part of the Community Genetics Forum 2006  
this film and discussion series explores the moral  
questions, dilemmas and controversies that  
accompany scientific advances in the field of genetics.



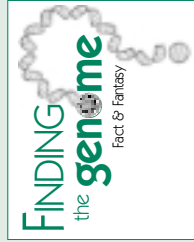
## Finding the Genome: Fact and Fantasy

Discussions following each film will be led by a geneticist and an ethicist from UNC, Duke or North Carolina Central University. Audiences may discuss such questions as:

- What can genes tell us about who we are?
- Are our genes our destiny?
- What is a mutation?
- Should we try to engineer the 'perfect' baby?
- What kind of genetic engineering can we do today?
- Is there a 'violence' gene?
- Who are my ancestors – really?
- How can I keep my genetic information private?

Following the film series is a communitywide forum. Everyone is invited—  
**Community Genetics Forum: Finding the Genome**

**Featuring Dr. Francis Collins,**  
**Director of the National Human Genome Research Institute and**  
**Leader of the Human Genome Project**  
**Saturday, Sept. 16 • 10 a.m. to 3 p.m.**  
**North Carolina School of Science and Mathematics, 1219 Broad St.**



This film series is part of a yearlong effort to engage Triangle-area communities in a meaningful dialogue about genetics.

The project is made possible by a partnership between:  
National Human Genome Research Institute; National Institutes of Health;  
Department of Health and Human Services \* USA; The University of North Carolina  
at Chapel Hill; The Carolina Center for Genome Sciences;  
Duke University's Institute for Genome Sciences and Policy and  
Center for the Study of Medical Ethics and Humanities; and Durham County Library.


For further information, please visit <http://genomics.unc.edu/cgf>.



**MOTHERLAND: A GENETIC JOURNEY**

(2003, 89 min., unrated)  
August 12 • 2 p.m.


Stanford L. Warren Library, 1201 Fayetteville St.

 Cut off from their ancestry by the 300-year-long slave trade, which uprooted 12 million people from Africa, three people are given the opportunity to reconnect with their ancestry through DNA searches. Come enjoy this fascinating journey into questions of ethnicity and history.

**GATTACA**

(1997, 101 min., PG-13)  
September 9 • 2 p.m.


Main Library, 300 N. Roxboro St.

 A futuristic story of a genetically 'imperfect' man. With an exciting and compelling plot line, the movie draws on concerns over technological developments that facilitate in-vitro fertilization, genetic engineering and diagnosis of genetic disorders. Watch as Ethan Hawke dares to fool the system in order to fulfill his dreams.

**FRANKENSTEIN**

(1931, 71 min., unrated)  
March 11 • 2 p.m.


Main Library, 300 N. Roxboro St.

 The classic! The timeless story of man's struggle to control, create, destroy and finally understand life. Based on Mary Shelley's 1831 novel of the same name, this film sends the clear message that irresponsible uses of technologies can have unconsidered consequences. Directed by James Whale, this film launched the career of unknown actor Boris Karloff and propelled horror films from the fringes of Hollywood to an accepted genre.

**LILO AND STITCH**

(2002, 85 min., PG)  
March 11 • 2 p.m.


Main Library, 300 N. Roxboro St.

 In this Disney children's film, "Experiment 626" is the result of illegal genetic research conducted on a planet far from earth. Although exiled to deep space, Stitch, a chaos-loving experimental creature, manages to make his way to Hawaii, where he is adopted by a young girl named Lilo. Lilo and her new "puppy" share hilarious adventures and learn that family can be more than mere heredity.

**TOMORROW'S CHILDREN**

(1934, 70 min., unrated)  
April 1 • 2 p.m.


Main Library, 300 N. Roxboro St.

 This 1934 anti-sterilization melodrama is an entertaining and thought-provoking period piece. When a family is told that all of its members must be sterilized or give up its welfare check, the eldest daughter, who is engaged to be married, resists. Filled with old-fashioned speechmaking and stereotypical characters, the film's arguments about eugenics prompt audiences to consider what society's views are today.

**THE MADNESS OF KING GEORGE**

(1994, 107 min., PG-13)  
May 13 • 2 p.m.


Southwest Branch Library, 3605 Shamon Rd.

 Based on a true story, this tale of madness and power is elegantly and humorously told with wit and superb acting. King George likely suffered from porphyria, a rare, inherited blood disorder whose hallmark symptom is reddish-brown urine. The historical account of 18<sup>th</sup>-century medical care and knowledge is fascinating and frightening. Nigel Hawthorne plays the mad royal with Helen Mirren as Queen Charlotte.

**X-MEN**

(2000, 104 min., PG-13)  
June 10 • 2 p.m.


Main Library, 300 N. Roxboro St.

 A tale of super-evolved mutants in a struggle against human oppressors, X-Men is an instant sci-fi classic. Director Bryan Singer combined special effects with an evolving plot to create a truly memorable cinematic experience.

**MINORITY REPORT**

(2002, 145 min., PG-13)  
July 8 • 2 p.m.

East Regional Library, 211 Lick Creek Ln.

 Steven Spielberg directs and Tom Cruise stars in this action-detective thriller set in Washington, D.C., in 2054. The pre-crime unit is hoping to go national with the motto "precrime - it works." This futuristic unit is able to arrest and convict murderers before they commit their crimes and boasts a 100% murder prevention rate. Find out what happens when the system comes crashing down.

# FINDING the genome

Fact & Fantasy

This film and discussion series explores the moral questions, dilemmas and controversies that accompany scientific advances in the field of genetics.

## FRANKENSTEIN

(1931, 71 min., unrated)

**March 11 • 2 p.m.**

Main Library

## LILO AND STITCH

(2002, 85 min., PG)

**March 11 • 2 p.m.**

Main Library

## TOMORROW'S CHILDREN

(1934, 70 min., unrated)

**April 1 • 2 p.m.**

Main Library

## THE MADNESS OF KING GEORGE

(1994, 107 min., PG-13)

**May 13 • 2 p.m.**

Southwest Branch Library

## X-MEN

(2000, 104 min., PG-13)

**June 10 • 2 p.m.**

Main Library

## MINORITY REPORT

(2002, 145 min., PG-13)

**July 8 • 2 p.m.**

East Regional Library

## MOTHERLAND: A GENETIC JOURNEY

(2003, 89 min., unrated)

**August 12 • 2 p.m.**

Stanford L. Warren Library

## GATTACA

(1997, 101 min., PG-13)

**September 9 • 2 p.m.**

Main Library

Part of the Community Genetics Forum 2006. For more information and future events: <http://genomics.unc.edu/cgf>.



### MAIN LIBRARY

**300 N. Roxboro St., 560-0130**

**Hours:** Mon. – Thurs. 9 a.m. – 9 p.m.;  
Fri. 9 a.m. – 6 p.m.; Sat. 9:30 a.m. – 6 p.m.;  
Sun. 2 – 6 p.m. (Sept. – May only)

### BRAGTOWN BRANCH

**3200 Dearborn Dr., 560-0210**

**Hours:** Mon. – Wed. 2 – 7 p.m.;  
Thurs. 2 – 6 p.m. (2 – 7 p.m. beginning  
June 1); Sat. 10 a.m. – 2 p.m.

### EAST REGIONAL LIBRARY (opening mid-May)

**211 Lick Creek Ln., 560-0203**

**Hours:** Mon. – Thurs. 9 a.m. – 9 p.m.;  
Fri. 9 a.m. – 6 p.m.; Sat. 9:30 a.m. – 6 p.m.

### MCDUGALD TERRACE

**1101 Lawson St., 560-0240**

**Hours:** Tues., Thurs. 9:30 a.m. – 6 p.m.

### NORTH DURHAM \*

**5120 N. Roxboro Rd., 560-0250**

**Riverview Shopping Center**

**Hours:** Mon. – Wed. 9 a.m. – 9 p.m.;  
Thurs. – Sat. 9:30 a.m. – 6 p.m.

### PARKWOOD \*

**5122 Revere Rd., 560-0260**

**Hours:** Mon. – Wed. 9 a.m. – 9 p.m.;  
Thurs. – Sat. 9:30 a.m. – 6 p.m.

### SALVATION ARMY BOYS & GIRLS CLUB

**810 N. Alston Ave., 560-0280**

**Hours:** Mon., Wed., Fri. 3 – 6 p.m.

### SOUTHWEST BRANCH \*

**3605 Shannon Rd., 560-0290**

**Hours:** Mon. – Wed. 9 a.m. – 9 p.m.;  
Thurs. – Sat. 9:30 a.m. – 6 p.m.

### STANFORD L. WARREN

**1201 Fayetteville St., 560-0270**

**Hours after Grand Re-opening:**

Mon. – Thurs. 9 a.m. – 9 p.m.;  
Fri. 9 a.m. – 6 p.m.; Sat. 9:30 a.m. – 6 p.m.

**\* Thursday hours 9 a.m. – 9 p.m.  
beginning June 1.**

Film series is sponsored by:  
National Human Genome Research Institute;  
National Institutes of Health; Department of  
Health and Human Services \* USA; The  
University of North Carolina at Chapel Hill;  
The Carolina Center for Genome Sciences;  
Duke University's Institute for Genome  
Sciences and Policy and Center for the  
Study of Medical Ethics and Humanities;  
and Durham County Library.



**FINDING**  
the **genome**  
Fact & Fantasy

This film series is part of a yearlong effort to engage Triangle-area communities in a meaningful dialogue about genetics.

The project is made possible by a partnership between: National Human Genome Research Institute; National Institutes of Health; Department of Health and Human Services \* USA; The University of North Carolina at Chapel Hill; The Carolina Center for Genome Sciences; Duke University's Institute for Genome Sciences and Policy and Center for the Study of Medical Ethics and Humanities; and Durham County Library.

**For further information, please visit <http://genomics.unc.edu/cgf>.**



THE UNIVERSITY  
of NORTH CAROLINA  
at CHAPEL HILL




**FINDING**  
the **genome**  
Fact & Fantasy

Part of the Community Genetics Forum 2006, this film and discussion series explores the moral questions, dilemmas and controversies that accompany scientific advances in the field of genetics.

MARCH 11, 2006  
2 P.M.

MAIN LIBRARY

FRANKENSTEIN

(1931, 71 min., unrated)  
Auditorium

LILO AND STITCH  
(2002, 85 min., PG)

Children's program room

**FRANKENSTEIN**

(1931, 71 min., unrated)



In March 1815, Mary Shelley, the author of *Frankenstein*, dreamed of her dead infant daughter held before a fire, rubbed vigorously and restored to life. At the time, scientists would not have wholly dismissed such a possibility. Could the dead be brought back to life? Could life arise spontaneously from inorganic matter? Scientists and physicians of her time, tantalized by the elusive boundary between life and death, probed it through experiments with other organisms, human anatomical studies, attempts to resuscitate drowning victims and experiments using electricity to restore life to the recently dead. The technology to create life does not yet exist, but we get closer every day to understanding the primordial 'soup' of chemicals that gave rise to the first self-reproducing proteins. A key step in the origin of life was the evolution of a molecule that could copy itself, which eventually led to our genetic code today. Scientists have begun to take inventories of the genetic code of various organisms to determine which genes are essential for life.

The story of *Frankenstein* has been told in many different ways ever since Mary Shelley's original version, but in every version of the story some constant ethical and social themes arise. Victor Frankenstein uses his ability as a scientist in ways that are out of bounds of social norms, using dead body parts for his project and creating a monster that society cannot accept. This raises the issue of scientists' responsibility to society. Should science achieve whatever it can in the hopes of great strides forward or should it be monitored and constrained by current social norms? In today's society, this debate is over the need to provide information to the public on the one hand and, on the other hand, to allow secrecy in order to move scientific discoveries forward in a free market system. Underlying all of these issues is the tension between human attempts to control the natural world through science and technology on the one hand and, on the other hand, remain in awe of nature's secrets.

**SOURCES:**

'Genomics and the Future' by Francis Collins and Karen Jeggalian in *Scientific American* December 1999, pgs. 50-55.

National Library of Medicine, *Frankenstein: Penetrating the Secrets of Nature*, <http://www.nlm.nih.gov/hmd/frankenstein/frankhome.html>

**LILO AND STITCH**

(2002, 85 min., PG)



Stitch is a genetically engineered creature from another planet. Let's talk about what 'genetically engineered' means.

First what is 'genetic'? Your body is composed of millions and millions of cells. Each cell, whether in your kidney, your brain, or the skin of your finger, carries an identical copy of the 46 chromosomes that are unique to you.

A chromosome is made up of thousands of genes. The genes are sections of your chromosome that when 'read' make a protein.

Genes are the individual instructions that tell our bodies how to develop and function; they govern our physical and medical characteristics, such as hair color, blood type and susceptibility to disease. Finally the material that makes a gene is called DNA. DNA could be compared to alphabet blocks that in a certain order code for certain proteins.

The idea behind genetic engineering is that by manipulating the DNA in our genes (our *genotype*) we can change our own outcomes like eye color, height or even predisposition to disease (our *phenotype*). What we need to discuss as a community is what this ability means and how can we use it responsibly.

## FILM SERIES CURTAIN SPEECH

For movie discussion leaders to use in introducing movies in film series:

Welcome to [insert movie title], the [1st] movie in our Community Genetics Forum 2006 film series, “Finding the Genome: Fact and Fantasy.”

This series is sponsored by the Durham County Library, UNC, Duke, and the National Human Genome Research Institute. It is part of a year-long project to promote discussion about the science and ethics of genetics. For more information about other films, an about other events in the project, we have flyers available, and a website.

The movies we are showing in this series were chosen because all of them raise questions about the science and ethics of advances in genetics and genetic research. Each movie does this in different ways. For example, today’s movie,

INSERT SENTENCE ON APPROPRIATE MOVIE HERE:

- **Frankenstein** doesn’t actually mention genes – it was made in 1937 – but it may make you think about the responsibilities of scientists.
- **Lilo & Stitch** might make you think about what a family is.
- **Tomorrow’s Children** may make you wonder if nature is more important than nurture, or if society’s views about genetics have changed since it was made in 1934.
- **The Madness of King George** raises questions about heredity and our changing views of mental illness.
- **X-Men** asks us to think about genetic discrimination.
- **Minority Report** raises questions about how well science can predict the future, and invites us to think about predictions based on genetic information.
- **Motherland, A Genetic Journey** raises questions about who our true relatives are and what that means for our sense of identity.
- **Gattaca** invites many questions, including questions about genetic diagnosis and genetic enhancement.

\*\*\*\*\*

My name is X, and my colleague here today is Y. Together, we’ll lead a short discussion after the movie. We invite everyone to stay for the discussion, have some refreshments, and share your thoughts and questions about the science and ethics of genetics. And now, [insert movie title].

---

AFTER MOVIE:

When opening the discussion, leaders reintroduce selves and ID their expertise and their institutions.

Ask very open questions to begin discussion, focusing on how audience views/responds to a character, an action, or the movie's general portrayal of genetics or of science. This should open things up. What follows is a short discussion guide that discussion leaders may use for each movie.

- **Frankenstein - Discussion:** What are responsible vs. irresponsible uses of genetics technologies? Can scientists really “make life”? What are the ethical issues involved in cloning human beings? What is currently happening in the introduction of human genetic materials into animals (the creation of “chimeras”)?
  - **Lilo and Stitch- Discussion:** Can Stitch be both “Experiment 626” and a puppy? How did Stitch get his special powers? How did Stitch become well-behaved when he loves destruction by nature?
  - **Tomorrow’s Children Discussion:** What is eugenics? What are the arguments for and against eugenic practices like sterilization? How can we tell the difference between “nature” and “nurture”? Have society’s views about eugenics changed since we have mapped the human genome? If so, how?
  - **The Madness of King George Discussion:** What does it mean to have a hereditary illness? How do rare illnesses get passed on? Will the same technologies that help people with inherited illness also put them at risk for discrimination?
  - **X-Men Discussion:** What is a mutation? What sorts of ‘phenotypes’ do mutations manifest? What is genetic discrimination?
  - **Minority Report Discussion:** How are genetic technologies currently used by criminal justice systems? Could these technologies be used in the future to prevent crimes? What balance can we strike between the value of privacy and improved safety through the use of such technologies?
  - **Motherland: A Genetic Journey Discussion:** How is ancestry testing done? What does it mean? How might ancestry testing affect group identities?
  - **Gattaca Discussion:** How does forensic DNA technology work, and how accurate is it? What ethical issues are raised by prenatal genetic diagnosis? What ethical issues are raised by genetic enhancement?
-

**Cyteen**

**Cyteen: the rebirth**

By C.J. Cherryh  
 About cloning, including much on nature vs. nurture and issues of identity.

**Cyteen: the vindication**

By C.J. Cherryh  
 About cloning, including much on nature vs. nurture and issues of identity.

**Beggars in Spain**

By Nancy Kress  
 SCIF Kress, N.

**The Left Hand of Darkness**

By Ursula K. Le Guin  
 A classic exploration of an alternative view of species-normal gender identity.

**Mendel's Dwarf**

By Simon Mawer  
 F/LF Mawer, S.

**My Sister's Keeper: a novel**

By Jody Picoult  
 F/LF Picoult, J.

**Welcome to the Monkey House:**

**a collection of short works**

By Kurt Vonnegut  
 The title story is about the social consequences of life extension. "Harrison Bergeron" is about preserving social equality through (mechanical) diminishment.

**Where Late the Sweet Birds Sang**

By Kate Wilhelm  
 An old novel about cloning by a master of speculative fiction.

This film series is part of a yearlong effort to engage Triangle-area communities in a meaningful dialogue about genetics.

The project is made possible

by a partnership between:

National Human Genome Research Institute;  
 National Institutes of Health;

Department of Health and Human Services \* USA;  
 The University of North Carolina at Chapel Hill; The

Carolina Center for Genome Sciences;

Duke University's Institute for Genome Sciences and Policy and Center for the Study of Medical Ethics and Humanities; and Durham County Library.

**For further information,**

**please visit <http://genomics.unc.edu/cgf>.**



**Fact & Fantasy**

Part of the Community Genetics Forum 2006, this film and discussion series explores the moral questions, dilemmas and controversies that accompany scientific advances in the field of genetics.

**SELECTED  
 NONFICTION  
 & FICTION  
 TITLES**



# NONFICTION

- \*Abraham Lincoln's DNA and Other Adventures in Genetics**  
By Phillip R. Reilly
- And the blood cried out: a prosecutor's spellbinding account of the power of DNA**  
By Harlan Levy 345.067 Levy
- \*Backdoor to Eugenics**  
By Troy Duster
- Bloodsworth: the true story of the first death row inmate exonerated by DNA**  
By Tim Junkin B Bloodsworth, K.
- Double Helix: a personal account of the discovery of the structure of DNA**  
By James D. Watson 574.8 Watson
- Expecting Adam: a true story of birth, rebirth, and everyday magic**  
By Martha Nibley Beck B Beck, M.
- \*From Chance to Choice: genetics and justice**  
By Allen Buchanan, et al.

\* Not at Durham County Library

**Genetic Maps and Human Imaginations: the limits of science in understanding who we are**  
By Barbara Katz Rothman 599.935 Rothman

**Genome: the autobiography of a species in 23 chapters**  
By Matt Ridley 599.935 Ridley

**The Genome War (How Craig Venter Tried to Capture the Code of Life and Save the World)**  
By James Shreeve BK DISC/611.018 S; BK TAPE/611.018 S

**Jacob's Ladder: the history of the human genome**  
By Henry Gee 599.935 Gee

**King of the code: science, ambition, and the untold story of the race for the human genome**  
By James Shreeve 611.018 Shreeve

**\*Mapping Fate: a memoir of family, risk, and genetic research**  
By Alice Wexler

**Mapping Human History: discovering the past through our genes**  
By Steve Olson 599.9 Olson

**\*The Selfish Gene**  
By Richard Dawkins

**Trace your roots with DNA: using genetic tests to explore your family tree**  
By Megan Smolenyak and Ann Turner 929.107 Smolenyak

**War against the weak: eugenics and America's campaign to create a master race**  
By Edwin Black 363.97 Black

# FICTION

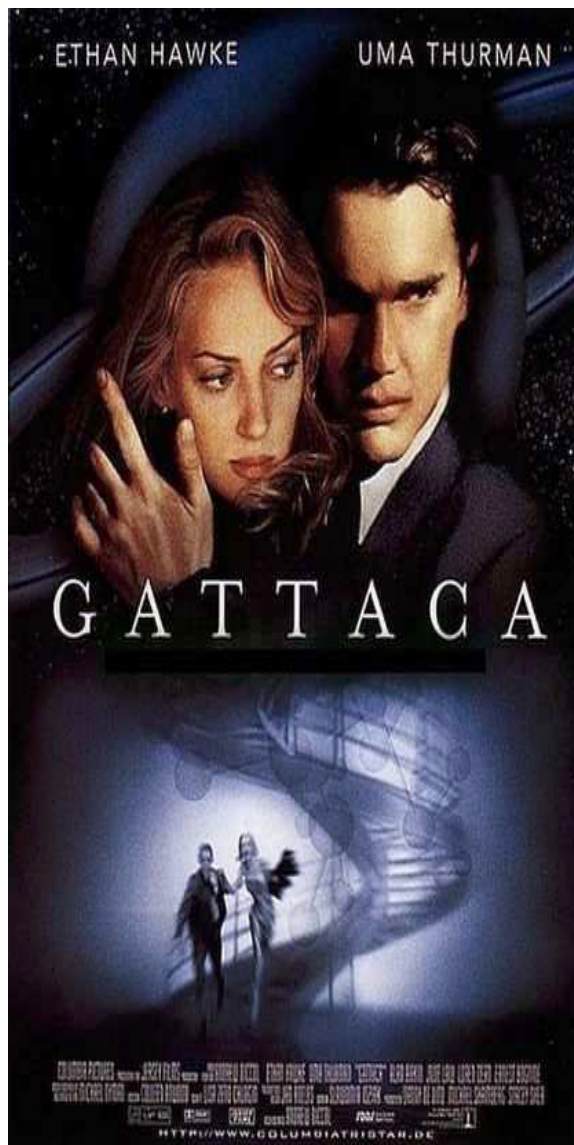
**Look to Windward**  
By Iain M. Banks SCIF Banks, I.  
Banks writes about a far-future society called the Culture in a number of novels. His Culture novels raise many issues related to genetic enhancement and extreme life extension. This novel crystallizes some issues about immortality in interesting ways.

**Queen of Angels**  
By Greg Bear SCIF Bear, G.  
Main character has committed to an expensive, high-maintenance, controversial enhancement.

**"Funes the Memorios,"**  
in the collection **Ficciones**  
By Jorge Luis Borges  
About perfect memory.

**Lilith's Brood**  
By Octavia Butler SCIF Butler, O.  
About the "yuck factor" – literally – and the political implications of chimerism.





## **GATTACA**

The story of an "imperfect " man in a society of designer-made perfection. With a compelling and exciting plot, the movie draws upon concerns over technological developments of in vitro fertilization, genetic engineering and prenatal diagnosis of genetic defects before birth. Are we simply the sum of our genes? Is all human achievement a product of one's genetic makeup? What makes us unique and what defines the human spirit? Come explore these questions as you watch one man beat insurmountable odds to fulfill his dreams.

### **FREE MOVIE**

6:30 pm

Thursday August 31st

202

MBRB

A discussion  
led by faculty  
from CCGS  
will follow  
the film

Sponsored by TIBBS  
and  
Community Genetics Forum



Directions to MBRB can be found at <http://ccbc.unc.edu/facilities/>

## Appendix D: Policy Roundtable

- Invitation
  - List of Attendees
  - Agenda
-



You are cordially invited to attend a

## **Policy Roundtable**

with

**Francis S. Collins, MD, PhD, Director**  
National Human Genome Research Institute

**William L. Roper, MD, MPH, Dean**  
School of Medicine  
University of North Carolina at Chapel Hill

**Thursday, September 14, 2006**  
**5:30-7:30 pm**

**Institute for Arts & Humanities**  
**Chapel Hill, North Carolina**

Part of a three-day community outreach effort to establish a dialogue among North Carolinians about genomics. The policy roundtable will examine cutting-edge policy issues pertaining to genetic information. Various stakeholders, such as key state health policy leaders, state hospital administrators, academic and private sector researchers, and local constituents, will participate.

**Genetics Policy Roundtable, Community Genetics Forum 2006  
Thursday, Sept. 14, 2006**

List of Attendees

Dr. Leslie Alexandre  
President and CEO  
North Carolina Biotechnology Center

Dr. Don Bailey  
Distinguished Fellow  
Research Triangle Institute

Dr. Leslie Biesecker  
Senior Investigator, Genetic Disease Research Branch  
Head, Human Development Section  
National Human Genome Research Institute

Mr. Vence Bonham  
Associate Investigator, Social and Behavioral Research Branch  
Chief, Education and Community Involvement Branch  
National Human Genome Research Institute

Dr. Dan Burns  
Senior Vice President, Research and Development  
Glaxo SmithKline

Dr. Francis Collins  
Director, National Human Genome Research Institute  
Senior Investigator, Genome Technology Branch  
National Human Genome Research Institute

Professor Lauren Dame  
Associate Director, Center for Genome Ethics, Law, and Policy  
Duke University

Dr. Jeffrey Dangel  
John N. Couch Professor, Department of Biology  
University of North Carolina-Chapel Hill

Dr. Allen Dobson  
Assistant Secretary for Health Policy and Medical Assistance  
North Carolina Department of Health and Human Services

Dr. Lynn Dressler  
Research Scholar, Center for Genetic Research Ethics and Law  
Case Western Reserve University  
University of North Carolina-Chapel Hill

---

Dr. Victor Dzau  
Chancellor for Health Affairs  
President and CEO of the Duke University Health System  
Duke University

Dr. H. Shelton Earp  
Professor and Director Lineberger Comprehensive Cancer Center  
Professor of Medicine and Pharmacology  
University of North Carolina-Chapel Hill

Dr. James P. Evans  
Associate Professor, Departments of Genetics and Medicine  
Director, Cancer Genetics Services  
Director, The Bryson Program in Human Genetics  
University of North Carolina-Chapel Hill

Dr. Phyllis Frosst  
Science Policy Analyst  
Acting Branch Chief of the Policy and Program Analysis Branch  
National Human Genome Research Institute

Dr. Greg Gibson  
Reynolds Distinguished Professor of Genetics  
North Carolina State University

Representative Rick Glazier  
North Carolina House of Representatives

Dr. Bernadette Gray-Little  
Provost  
University of North Carolina-Chapel Hill

Mr. Robert J. Greczyn, Jr.  
President and CEO  
Blue Cross-Blue Shield of North Carolina

Dr. Alan Guttmacher  
Director, Office of Policy, Communications and Education  
Deputy Director  
National Human Genome Research Institute

Dr. Kenneth Harewood  
Director, Biomedical/Biotechnology Research Institute  
North Carolina Central University

Representative Verla Insko  
North Carolina House of Representatives

Ms. Nancy MP King  
Professor of Social Medicine  
University of North Carolina at Chapel Hill

---

Senator Eleanor Kinnaird  
North Carolina Senate

Dr. Steven Kleeberger  
Chief of the Laboratory of Respiratory Biology  
Director of the Environmental Genetics research  
National Institute of Environmental Health Sciences

Dr. Terry Magnuson  
Sarah Graham Kenan Professor  
Chair, Department of Genetics  
Director, Carolina Center for Genome Sciences  
University of North Carolina at Chapel Hill

Dr. Howard L. McLeod  
Fred Eshelman Distinguished Professor  
Division of Pharmacotherapy and Experimental Therapeutics  
University of North Carolina at Chapel Hill

Dr. Holly Riddle  
Executive Director  
North Carolina Council on Developmental Disabilities

Dr. William L. Roper  
Dean of the School of Medicine  
Vice Chancellor for Medical Affairs  
CEO of the UNC Health Care System  
University of North Carolina-Chapel Hill

Mr. Adam Searing  
Project Director  
North Carolina Healthcare Access Coalition

Dr. Elizabeth Thomson  
Program Director, Ethical, Legal, and Social Implications Research  
National Human Genome Research Institute

Dr. Kenneth Tindall  
Senior Vice President, Science & Business Development  
North Carolina Biotechnology Center

Dr. Diane Wagener  
Program Manager, Genomics and Statistical Genetics Research Program.  
Research Triangle Institute

Dr. Tony Waldrop  
Vice Chancellor for Research and Economic Development  
University of North Carolina at Chapel Hill

---

**Community Genetics Forum 2006 Policy Roundtable Agenda**

Institute of Arts and Humanities  
University of North Carolina at Chapel Hill  
5:00 pm -7:30 pm

- 5:00-5:30 Participants arrive.  
Nametags.  
Drinks and plattered hors d'oeuvres.  
Greet and Meet.
- 5:30 Buffet Dinner set out for participants.
- 5:45 Dean William Roper – opening remarks.  
a. Welcome  
b. Opening event of a three day Community Genetics Forum 2006 designed to establish a conversation about the science and ethics of genetics.  
c. Introduce Dr. Francis Collins, Director National Human Genome Research Institute
- 6:00 Dr. Collins introduces first topic – Federal Genetic Nondiscrimination Bill  
Dr. Collins introduces second topic when appropriate – DNA Banking
- 6:45 Break
- 7:00 Reseat for plated dessert
- 7:30 End
-

## Appendix E: Evaluation

- Demographic Information Form
  - Evaluation Form
  - Survey Result: How did you hear about the CGF?
-



## Community Genetics Forum 2006

Thank you for joining us for today's Community Genetics Forum. We look forward to your participation and feedback. We hoped the Forum would attract a broad range of people from our community and are interested in learning some information about you.

Please provide the information below. We do not need your name.

1. What year were you born? \_\_\_\_\_
2. What is your gender? (circle) Female      Male
3. What is your zip code? \_\_\_\_\_
4. How do you describe yourself: (check one or more; you may check more than one)

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Hispanic/Latino

Other (please specify): \_\_\_\_\_

5. Last week were you (circle all that apply)?
  - a. working full time
  - b. working part-time
  - c. student      high school      undergraduate      graduate
  - d. retired
  - e. unemployed
6. If employed, what is your primary occupation? \_\_\_\_\_
7. If you are a student, what is your school, college or university?  
\_\_\_\_\_



## Community Genetics Forum 2006 Evaluation Survey

Thank you for attending today's Community Genetics Forum. Please complete this feedback form and leave at the registration desk. We appreciate your comments about the event.

**1. What is your overall evaluation of this event:**

Excellent  Good  Fair  Poor

**2. What topics did you find most valuable:**

---

---

**3. After today's forum, do you feel more informed about: (check all that apply)**

genetics and health  ethical, legal, social issues  genetic research

other: (please describe) \_\_\_\_\_

**4. What issues would you like to learn more about:**

genetics and health  ethical, legal, social issues  genetic research

other: (please describe) \_\_\_\_\_

**5. Did you have an opportunity and feel encouraged to express your opinions and ideas?**

Yes  No Comments: \_\_\_\_\_

**6. Were your questions adequately answered?**

Yes  No Comments: \_\_\_\_\_

**7. If you are a student, would you consider a career in: (check all that apply)**

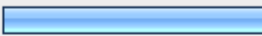

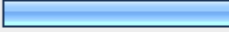



genetics/healthcare  ethical, legal, social issues  genetic research

not a student  other

**8. Did you find the program on Thursday evening with the graduate students and representatives from NHGRI useful? Why or why not?**

**Additional comments:**



3. How did you hear about the Community Genetics Forum?			Response Percent	Response Count
e-mail announcement		50.0%	35	
poster		7.1%	5	
colleague/friend		44.3%	31	
internet		2.9%	2	
CGF website		2.9%	2	
Other (please specify)		15.7%	11	
	<i>answered question</i>		<b>70</b>	
	<i>skipped question</i>		<b>1</b>	