
Report on the

Community Genetics Forum

2006

prepared for the
National Human Genome Research Institute



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Introduction

This document describes the experience of the University of North Carolina at Chapel Hill in implementing the National Human Genome Research Institute sponsored project, Community Genetics Forum 2006. This document will be most useful for those planning on starting and sustaining like-minded community outreach projects. Our successes and ‘lessons learned’ will be frankly discussed. We have organized this document discussing first some general topics, goals and challenges, second some of the ‘pre-events’ we held in preparation for our final forum, and third a description of the planning and outcome of our final event with our evaluatory component. The organizers for this event were a core group of researchers involved with an Ethical, Legal and Social Issues (ELSI) in Genetics program planning grant, Scale-Up: Large Sample Gene Discovery and Disclosure. This group of scholars and researchers were interested in ELSI topics in genetics and therefore were eager for the opportunity to reach out to the community both to offer genetic science information and to encourage discussion of the ever-changing technology and knowledge in this exciting and challenging area. The core group of five responsible for carrying out the grant has backgrounds in areas as diverse as philosophy to internal medicine to law (See Table 1). With the exception of one member, the core group comes from the Department of Social Medicine, part of the School of Medicine at the University of North Carolina at Chapel Hill.

Table 1.

Barbra Bluestone Rothschild, M.D. (Project Director)	Assistant Professor	Social Medicine
Giselle Corbie-Smith, M.D.	Associate Professor Associate Professor	Social Medicine Medicine
Nancy M.P. King, JD	Professor	Social Medicine
Felicia Mebane, Ph.D.	Assistant Professor	Heath Policy and Administration
Rebecca Walker, Ph.D.	Assistant Professor Adjunct Assistant Professor	Social Medicine Philosophy

The other members of our ELSI planning group served as our internal advisory group. They were helpful in advising us every step of the way and in providing administrative assistance and leadership for the forum events themselves.

- Don Bailey, PhD
- Gail Henderson, PhD
- John Conley, JD
- Arlene Davis, JD
- Jim Evans, MD, PhD
- Terry Magnuson, PhD
- Cynthia Powell, MD
- Debra Skinner, PhD
- Patrick Sullivan, PhD
- Marcia Van Riper, PhD

During the proposal planning process we formed an external advisory group. We asked groups that had already well-established links with the community. Organizations and members were added as we discovered those that were interested in engaging in a conversation about the future of genetics, encouraging young people to pursue a career in genetics or engaging the academic world in a discussion of ELSI issues in genetics. The members of our external advisory board are as follows:

■ [Duke University Genome Ethics and Law Program \(GELP\)](#)

Bob Cook-Deegan, Priscilla Wald

GELP is part of the Duke University Institute for Genome Sciences and Policy. It was created to foster ethically responsible and socially beneficial uses of genome science, while addressing the complex ethical, legal, social and policy impacts of the genome revolution.

■ [The Sonja Haynes Stone Center for Black Culture and History](#)

Joseph Jordan

The mission of the Stone Center is to encourage and support the critical examination of all dimensions of African-American and African diaspora cultures through sustained

and open discussion, dialogue and debate, and to enhance the intellectual and socio-cultural climate at the University of North Carolina at Chapel Hill and in communities beyond the campus boundaries.

■ **The UNC Program on Ethnicity, Culture, and Health Outcomes (ECHO)**

Paul Godley, Anissa Vines

ECHO is committed to eliminating disparities in health status and health outcomes among vulnerable and underserved populations through culturally sensitive service in North Carolina communities, multidisciplinary training and education, and evidence-based research. One of ECHO's primary goals is to help communities identify and solve community health problems through facilitation of increased student and faculty involvement in community oriented research.

■ **Historically Black Colleges and Universities (HBCU) Health Promotion Alliance**

Anissa Vines

The HBCU Health Promotion Alliance is a partnership among four HBCU's and three state agencies in North Carolina. The partners are North Carolina A&T State University, St. Augustine's College, Fayetteville State University and North Carolina Central University along with North Carolina Office Of Minority Health, the Division of Medical Assistance and the Office of Rural Health. The partnership's goal is to improve the health status of the community by examining and addressing health behavior issues and to advocate for access and removal of barriers to health care services. Many of the Alliance's former and current projects involve community outreach, engagement, and education in areas such as using entertainment as a method of imparting health education, HIV and STD prevention, and tissue and organ donation.

■ **Center for Aging and Diversity**

Peggye Dillworth-Anderson

The Center for Aging and Diversity is part of the UNC Institute on Aging. Its mission is to address, through research and training, health disparities in later life, provide a forum in which to discuss and examine ethnic, racial and cultural variation in life course processes and to disseminate research findings to the academic and lay community on the health of older diverse populations.

- [Center on Innovations in Health Disparities Research](#)

Chris McQuiston

The Center for Innovation in Health Disparities Research (CIHDR) is a partnership between the Departments of Nursing at Winston-Salem State University, North Carolina Central University, and The University of North Carolina at Chapel Hill. CIHDR's primary goal is to increase the capacity for culturally competent nursing research. The Center mentors faculty and students, funds pilot studies, and develops and implements educational programs designed to promote innovative methodologies in health disparities research.

- [Durham County Library](#)

Sandy Sweitzer

The Durham County Library's mission is to provide communities and individuals with books, services, and other resources that inform, inspire learning, cultivate understanding and excite the imagination.

- [The North Carolina School of Science and Mathematics](#)

Steve Warshaw

The North Carolina School of Science and Mathematics is a boarding high school for students of all backgrounds talented in science and math. It has an additional purpose of teaching science and math teachers around the state ways to improve science and math educational methods at the local high school level. NCSSM is well connected to communities throughout the state.

- [The North Carolina Biotechnology Center](#)

Ken Tindall

The North Carolina Biotechnology Center is a private, non-profit corporation created by the State in 1984 and supported by the General Assembly. The North Carolina Genomics and Bioinformatics Consortium was created by the North Carolina Biotechnology Center specifically to promote genomics, proteomics, and bioinformatics for economic benefit to North Carolina. The Consortium's members include the private industry in North Carolina that conducts genetic research and development.

- [Guilford Genomic Medicine Initiative \(GGMI\)](#)

Donna Spoon, Vince Henrich

The GGMI is a Department of Defense-funded partnership of Duke University's Center

for Human Genetics and Department of Medicine, UNC-Greensboro's Institute for Health, Science, and Society, and the Moses Cone Health System, to develop a comprehensive effort to bring genomic medicine into community health care.

■ **Carolina Center for Genome Science (CCGS)**

Terry Magnuson

This group is made up of UNC faculty with well-established research programs in the evolving field of genomics. 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. The CCGS also recognizes the importance of understanding the societal implications of genomic discoveries and has brought together a group of social scientists, physicians and legal experts with a common interest in healthcare education as well as public policy. 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.

■ **Parr Center for Ethics**

Jan Boxill

The Parr Center for Ethics is the public face of the University's commitment to ethics. It sponsors research, teaching, and discussion of ethical issues that are important to the university and the communities it serves. Their goal is to promote ethical development by providing the necessary resources - theoretical development, empirical knowledge, and actual opportunities - to explore and advance our understanding of ethical issues. The Parr Center will provide some financial support for Colloquium Day #1 and the seminar series, and will contribute website resources to promote discussion of ELSI issues using an already established "ask an ethics question" web module.

The following organizations and advisors were added later during the process:

■ **The Lerner Day School**

Bryna Rapp

The Lerner School of Durham/Chapel Hill is a private, independent elementary and

preschool committed to excellence in secular studies and Jewish learning. The Lerner School is open to all children of the Jewish community whose parent(s) embrace the mission of the school.

■ **Partnership for Minority Advancement in the Biomedical Sciences (PMABS)**

PMABS collaborates with partner Universities, most of which are primarily minority serving institutions, to strengthen Biology departments, offer enrichment to students and professors, supply lab equipment and other services. We partnered closely with PMABS and offered an extensive enrichment program to students who could get to Chapel Hill for the main Forum.

■ **SPIRE**

SPIRE is an innovative post-doc training program that combines traditional research at UNC-CH with teaching at seven of North Carolina's historically minority universities. SPIRE is designed to support PMABS' partner universities in their development of underrepresented students in the life sciences.

■ **Triangle Gay and Lesbian Association**

An organization to serve the need of the gay and lesbian population of the Triangle, NC area. They are a clearinghouse for events, run hotlines, and sponsor social events.

■ **North Carolina Association of Biomedical Research (NCABR)**

The mission of the NCABR is to promote public understanding and support for biomedical research. To date, more than 2,000 North Carolina K-12 teachers have participated in NCABR's science education programs, more than a thousand North Carolinians have attended an NCABR public forum to debate biomedical research issues, and dozens of members of the North Carolina and national media have attended an NCABR science journalism program. NCABR agreed to assist in our marketing efforts.

■ **Training Initiative in Biological and Biomedical Sciences (TIBBS)**

TIBBS provides graduate students in the School of Medicine, Chemistry, and Biology Departments professional development and training, awareness of career opportunities, teaching opportunities, social events, and networking activities. We sponsored a showing of Gattaca with TIBBS. They were very helpful in the encouraging graduate students and post-docs to attend the final Forum.

Participants from NHGRI who were invaluable in leading breakout sessions and generating excitement for the event are listed below:

- Les Biesecker, M.D., Senior Investigator, Genetic Disease Research Branch
- Vence Bonham, J.D., Chief, Education & Community Involvement Branch
- Francis Collins, M.D., Ph.D., Director, NHGRI
- Carla Easter, Ph.D., Science Education Specialist
- Milton English, Ph.D., Postdoctoral Fellow
- Phyllis Frosst, Ph.D., Acting Chief, Policy & Program Analysis Branch, Science Policy Analyst
- Eric Green, M.D., Ph.D., Scientific Director, NHGRI
- Alan Guttmacher, M.D., Deputy Director, NHGRI
- Sarah Harding, M.P.H., Community Outreach Analyst
- Jean Jenkins, R.N., Ph.D., F.A.A.N., Senior Clinical Advisor
- Rebecca Kolberg, Deputy Chief, Communications & Public Liaison Branch
- Dale Lea, R.N., M.P.H., C.G.G., F.A.A.N., Health Educator
- Vivian Ota Wang, Ph.D., Senior Advisor, Office of Behavioral & Social Sciences Research
- Laura Rodriguez, Ph.D., Health Policy Analyst, Special Advisor to the Director
- Elizabeth Thomson, R.N., M.S., Program Director, ELSI Program

Overall Forum Goals

The Community Genetics Forum 2006 is represented by a year's (and beyond) worth of events, networking, and outreach. The goals for this yearlong process originated with the planning document we submitted to the NHGRI in response to their Request for Applications. These goals were developed in conjunction with the NHGRI taking into consideration their priorities and our sense of our community. They were:

- a) To increase knowledge and awareness of genetic science in our community.
- b) To engage our community in a conversation about issues in genetic science.
- c) To identify and discuss ELSI issues of concern to the community
- d) To increase awareness of career options in genetic and ELSI research
- e) To establish or strengthen relationships between community groups and genomics/ELSI scholars and researchers
- f) To provide community leaders, biotechnology executives and science teachers with sources for genetic science information and tools to sustain continuing dialogue around ELSI issues
- g) To engage policymakers in an informed discussion on current genetic policy issues in North Carolina.
- h) To communicate community concerns/ideas to decision-makers in the genomics/ELSI arena
- i) To facilitate informed consideration of the promise, potential benefits, risks, and burdens of genetic research and testing that affects groups and communities in North Carolina.

All of the events were planned with one or more of these goals in mind. Prior to our final event, we held a number of smaller events that were designed to address one of the specific goals above and to inform the plan for our final Forum on a Friday/Saturday in September. These smaller events will be fully described later in this document, but included:

- i) Community Conversations – Scheduled conversations with specific community groups to provide basic genetic science information and solicit thoughts and opinions on today's genetic issues.

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- ii) Finding the Genome Film Series – A film with some element of genetic science (from Spiderman to Gattaca) was shown once a week at the Durham County Public Library and geneticists and ethicists led discussions afterwards.
 - iii) Graduate Student Movie and Discussion
 - iv) NHGRI speakers for NC Science Teacher Conferences – Speakers from NHGRI were provided to conferences for NC science teachers.

Our final event was a three day forum for the community, policymakers, and academicians. A detailed schedule of these three days appears in Appendix B. In brief the events were:

Thursday, September 14

Nursing in the Genomic Era & the Importance of Family History – Two sessions of nursing continuing education on genetics and family history.

Community Genetics Forum: Policy Roundtable – A roundtable with Dr. Francis Collins and community activists, political leaders, and businessmen discussing privacy and other topical issues in genetics and policy.

HBCU students and Area Undergraduates Welcoming Program – The beginning of a program that welcomed HBCU students from all over North Carolina to the Forum weekend.

Friday, September 15

Breakfast for Graduate Students Involved with Maximizing Student Diversity – A breakfast for graduate students in the sciences interested in issues of diversity with Dr. Collins.

Finding the Genome: Group Interests in Genetic Research and Testing – A symposium with Dr. Francis Collins, Dr. Dena Davis, and Ms. Debra Harry on the various perspectives of group genetics testing and research with breakout sessions.

Additional Activities for Undergraduates, Graduate Students and Post-Docs- A lunch, career panel, lab tours were some of the activities available to students.

Saturday, September 16

The Human Genome and Being Human: A Community Conversation on our DNA, Health, Values and Heritage – A community wide event with speakers and a town hall on genetics science and ethics with breakout sessions tailored to the community.

Starting Engagement

We completed our plan with input and advice from NHGRI, a pattern that was to continue throughout the forum planning process. We developed a 'roadmap' to negotiate our way through the various milestones we needed to reach to accomplish our goals. This map was continually updated and modified to fit changing partnerships, but for the most part it was a very helpful tool in keeping track of our timeline and progress. Below we describe some of the tasks we completed in the first six months before the logistics of the Forum became primary.

- Identifying Communities
- Establishing Relationships with Communities
- Examples of Community Building Meetings
- Establishing and Pursuing Relationships with Other Institutions
- Encouraging Careers in Genetics

Identifying Communities

We began this endeavor with many extensive and helpful discussions on the definition of community. This was an essential place to begin as the definition would affect every aspect of the project from our audience to the subject matter. Definitions were proffered that ranged from geographic to ethnic to religious to educational level. We agreed that a single person can belong to many different communities at one time some even seemingly at odds with each other. This was important as we wanted to be both inclusive but able to target specific populations. We also needed to be realistic about what we could accomplish. We decided that the state of North Carolina was a community that we could reach with already organized event meetings such as science teacher conferences. We decided for the type of intensive outreach we had planned a smaller geographic area was appropriate and this was the Triangle area (Raleigh, Durham, and Chapel Hill) and surrounding counties (Wake, Durham, Orange, Chatham, Johnston). Thus our initial definition was clearly geographic. We then turned to the funder. What does the funder believe is community? In this case, our perception was that the funder preferred the emphasis be placed on underserved ethnic communities. What does underserved mean? Ethnic communities in our geographic area with a history of marginalization or socio-economic/educational disadvantage fit the definition of underserved. In addition, communities who have not been engaged in the discussion of genetics in the past were targeted. These may be the same communities that may have a vested interest in both the ongoing allocation of resources in genetic research and the possibility of discrimination

as a result of genetic research and testing. In our case this meant our African-American population would be a target population and that because of demographics it made a lot of sense to plan many of our activities in Durham rather than other parts of the Triangle region. From early on, we had some difficulty explaining this project to both academic and community groups. To help yourself in this endeavor remember and clarify your goal. This project is about outreach with an evaluatory component. This project is not research or quality assurance. This is a difference that will influence many of your decisions. For instance, when thinking about your community you are not bound by an accurate reflective demographic representation. You are not bound by specific questions or hypotheses. In a larger sense your goal is to generate discussion and interest about genetics in your target community. It is helpful early on to make a list of what advantages this will bring to the community you are trying to engage because that is one of the first questions they will ask.

Establishing Relationships with Communities

As we started our initial outreach attempts it became apparent that it was essential to think carefully about our approach to the community. As the long history of town/gown tensions reflect, the academic center is not always in touch with the community that surrounds it. Is there a strong relationship between your institution and your community? Is there a history of distrust or a history of mutual benefit? Is there a large medical center associated with your institution? What is the general perception of the medical institution within your community? If it is positive, are there outreach arms already in place that reach the community of interest that your team can leverage for the project? If negative, how can you best distance your goal from the negative history towards a positive future? In general people who take an active role in their community know best how to reach that community so it is essential to involve community representatives in your process. How do you convince community representatives that this is a project worth pursuing? The approach to these questions formed our approach to the community.

Early on in our process we called an area health department to discuss support and involvement. One health department representative who serves the local Latino population said, "This all sounds very interesting but what is in it for the people I serve? They don't want to sound ungrateful for all the medical care that UNC provides but it feels like every medical student over there is doing a research project on this population and they are feeling a little used. You need to be clear about how this fits in with their priorities." This was very sound advice. We discussed this extensively and arrived at these priorities and advantages of participating:

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- a) Empowerment: Knowledge is power. Learning about genetics can help you manage you and your family's health.
 - b) A Voice: This project enables you to have a direct voice to those people who make decisions about how resources get directed in genetics research. Like research about diabetes and heart disease but not about behavior? This is your opportunity to tell the government in a loud and direct way.
 - c) Access: Learn the arguments for increased access to genetic technology.
 - d) Opinion: Experiences offered by this Forum can assist you in defining and refining your own opinions about ethical and scientific issues in genetics.

We refined and expanded on these reasons. We also listened to our audience when explaining them. Do they make sense to the community? Do they resonate as useful and truthful?

Examples of Community Building Meetings

From the beginning of the project, our core group met every two weeks with many emails and phone calls in between meetings. We distributed our outreach efforts among the team by developing a list of possible contacts and then assigning them to team members for further development. Even at these early meetings, an important aim was to establish a date and time of an event in order to keep our partners engaged and active with the project. These initial discussions were a platform to ask questions about the community represented by the partner and to strategize marketing and outreach approaches with that community. We also used a 'snowball' effect to foster further collaborations by asking each of our original groups for suggestions for other partners. As an example of some of these early meetings and our notes from them follows

North Carolina Central University

- Purpose:** Initiate a dialogue with North Carolina Central University and explore avenues of collaboration.
- Result:** Discussed ways the Forum could meet needs of students at MSUs. Outlined plan to market Forum to NCCU students and faculty through classes and listservs and community conversations.
- Outcome:** We followed the advice of our NCCU advisors. The Forum attracted faculty and staff from NCCU, one of whom became a mentoree of the ELSI project.

The North Carolina School of Science and Math

- Purpose:** Begin planning September event at this venue and discuss student involvement.
- Result:** Initial planning for logistics of the Saturday Forum.
- Outcome:** The Community Forum took place at the North Carolina School of Science and Mathematics. The location was very successful in attracting community members.

Durham County Library

- Purpose:** Continue planning film series, Finding the Genome.
- Result:** Films were ordered and discussion leaders were chosen from UNC and Duke.
- Outcome:** A film was shown once a month with a discussion of genetic science and ethical issues following. The Film Series was also very helpful in marketing the final Forum events.

The Sonja Haynes Stone Center for Black Culture and History

- Purpose:** Discuss enhancing diversity among attendees at the Friday symposium. Plan reception for two of our speakers, Dena Davis and Debra Harry, at the Stone Center on Friday afternoon.
- Result:** The Stone Center ran stories about the Forum in their newsletter in the weeks leading up to the event.
- Outcome:** We had very good African-American student attendance at the Finding the Genome: Group Interests in Genetic Research and Testing event at UNC.

Parr Center for Ethics

- Purpose:** Discuss marketing/advertising strategy.
- Result:** The Parr Center assisted us in marketing the Forum to the University Community.
- Outcome:** We were overflowing for the Friday UNC event.

Duke Community Relations

- Purpose:** The Duke Community Relations department is extremely well connected with the Durham, Chapel Hill community and runs several successful community health outreach programs. Discuss partnership possibilities especially in the area of marketing.
- Result:** Duke Community Relations advertised our event through their listserv. They were especially helpful in advertising the Forum to the Durham African-American Community.

Adventures in Ideas

- Purpose:** Adventures in Ideas is a UNC program that invites community members to participate in various subject lectures and forums.
- Result:** Although they did not participate in the Forum, we advised them on programming that would appeal to a more diverse community forum and recommended faculty members for such a program.

What's the Big Idea

- Purpose:** Another partnership possibility and networking opportunity to enhance attendance.
- Result:** After discussing the Community Genetics Forum, What's the Big Idea convened a human genetics forum for the public to follow-up the CGF.

SPIRE, Carolina Center for Genome Sciences

- Purpose:** The Spire program at UNC works to increase minority education and participation in the sciences.
- Result:** This meeting resulted in a close working relationship with the SPIRE program. We identified many areas of collaboration.
- Outcome:** We were able to connect with the SPIRE fellows and encourage participation of HBCU undergraduates in a specially designed overnight program during the Forum. We were also able to design an extensive parallel track for graduate students at the Friday event designed to spark interest in genetic science and careers.

Triangle Community Works

Purpose: TCW is an integrative community program that aims to assist the Triangle's gay, lesbian and transgender population. We met with Jan to arrange a community conversation

Result: We were unable to schedule a community conversation but did establish a good working rapport with this organization.

Outcome: Members of the organization attended the Community Genetics Forum.

Ideas! Coffee House

Purpose: The Ideas! Coffee House is located in a diverse neighborhood in southern Durham.

Result: We scheduled a community conversation that took place at the Ideas! Coffee House.

Outcome: The feedback and topic selection from this community conversation helped to inform the breakout sessions for Saturday's CGF conference.

Medical School Curriculum Committee

Purpose: We wanted to address the medical community.

Result: The Curriculum Committee integrated Dr. Collins' visit into the first year curriculum, making the event required for first year students.

Outcome: We were able to attract over 600 members of our medical community to the talks by Dr. Collins, Dr. Davis, and Dr. Harry. The comments showed that many had not reflected on the issues presented at Finding the Genome: Group Interests in Genetic Research and Testing.

Establishing and Pursuing Relationships with Other Institutions

Because our emphasis on the first Forum, Finding the Genome: Group Interests in Genetic Research and Testing, was the academic community it was important to reach out to the many academic institutions in our area for participation and support. From the beginning of our application for this project we were interested in pursuing a relationship with Duke University because of their strong background in genetic and ELSI (Ethical, Legal, and Social Issues) research. Bob Cook-Deegan, Lauren Dame, and their staff at the Institute for Genome

Science and Policy's Center for Genome Ethics, Law and Policy were very helpful throughout the process.

We also engaged North Carolina's historically black college and university system. As one of the project's specific goals was to encourage careers in genetics especially among minorities, this partnership was an excellent arrangement to reach minority students interested in science. We attempted to arrange this partnership in two ways. One was by contacting the Chairpersons of Biology of the various institutions directly. This was very effective in encouraging students from these institutions to attend our final Forum. The other was by working with the SPIRE post-doctoral program and PMABS (see above). Using these two very effective programs we were able to partner with the following institutions:

- [Elizabeth City State University](#)
- [Fayetteville State University](#)
- [Johnson C. Smith University](#)
- [Livingstone College](#)
- [North Carolina A&T University](#)
- [North Carolina Central University](#)
- [Shaw University](#)
- [UNC Pembroke](#)
- [Winston Salem State University](#)

This partnership allowed us to develop a program especially for undergraduates from these institutions interested in careers in genetics. If the institution could arrange transportation to Chapel Hill, we arranged for hotel, meals, and transport to the Forum. This track included lab tours, talks by graduate students and NHGRI personnel, and the opportunity to hear the talks by Dr. Collins and our other guests with the rest of our academic community. This was valuable for the students who were able to come but also allowed us an opportunity to establish a precedent for this type of programming at our University. In addition, we now have continuing relationships with many of the faculty members of these institutions.

The Appendix contains some of the marketing materials and sign-up forms we used with these institutions to encourage students to get involved with the final Forum days.

Encouraging Careers in Genetics

Engaging Area High Schools- Engaging high school students was an important goal of our Community Genetics Forum 2006 as North Carolina has historically put an emphasis on education. We were lucky to have the North Carolina School of Science and Mathematics, a public boarding school for high school students talented in science and mathematics, as a partner for this project. We conducted community conversations with three biology classes at the school to gauge what high school students might be interested in discussing. We had case scenarios prepared for ELSI issues and opened the conversation up to questions and comments. Many students were very interested in exploring the ethical issues brought out by advancing technologies but they were equally interested in hearing about the newest science and the latest in genetic research news which inspired a well-attended breakout session, What's New and Exciting in Genomics Research!?!? . We contacted the Durham Public Schools through many different avenues. We emailed the science curriculum directors, we discussed the project one on one with a school board member, and we sent announcements to a number of administrators. We also contacted the science classes in the area private schools, many of whom used attendance at our Saturday conference as an extra credit project for their classes.

Outreach to Statewide Educational Forums- Using Google and the State of North Carolina State Board of Education website we identified state wide organizations that were involved in teacher training in the sciences. We identified upcoming teacher conference opportunities and then contacted the organizers with an offer of a speaker from the National Human Genome Research Institute on genetics in the classroom. Two organizations took us up on our offer. The Department of Education of North Carolina sponsors a Summer Science Leadership Institute for county science curriculum planners and administrators. NHGRI provided a keynote speaker for this Institute who was very well-received. We also contacted the North Carolina Science Teacher Association which holds a professional development Institute annually. They also were pleased to welcome a speaker from NHGRI. When making these negotiations we explained our efforts to keep genetics a 'conversation' in North Carolina in 2006. We have since received requests from science teachers across the state for speakers from UNC on the subject of genetics both science and ethics. For instance a teacher from a Fayetteville high school found our website and contacted us for a speaker on DNA day. We were able to connect her with the DNA day efforts being made by our graduate students at UNC.

Organization- We used the aforementioned outreach techniques to familiarize ourselves with our community's needs and opinions. We took notes at each meeting. When we had events prior to the Forum (see below) we had forms designed to capture specific aspects of the audience, for instance demographics, questions asked, what is the mood in the room, etc. These notes assisted us in designing the final Forum with appropriately interesting breakout sessions, and outreach methods. We had a half-time assistant that kept the notes and organized the meetings. She was committed to the project and this type of organizational structure was invaluable to our experience.

Finding the Genome:

Fact and Fantasy Movie Series Partnership with Durham County Library

From early on, we felt that a partnership with the local public library system would be an excellent way of reaching out to a community that academic attempts at outreach often miss. The Durham County Library is the most visited building in Downtown Durham and seemed to be a perfect partner. We were lucky that they were so receptive to our ideas. In conjunction with their programming department we brainstormed about films that would be appropriate. We made a list of films that had some sort of genetics theme, was PG-13, PG, or G, might have some popular appeal, and that were available to us. We developed handouts to go with each film. These handouts explained a little of the science behind the genetic theme in each film and broke down some of the more 'fantasy' themes. We also explored an ethical theme in each film. A film was shown each month starting in March leading up to the final Forum in September so we could also use this as an opportunity to market the Forum. A panel of experts, made up of a scientist and ethicist and social commentary expert was available to discuss the issues with the audience afterwards.

Some films were particularly effective with teens like Spiderman, where Jim Evans, a geneticist from UNC discussed the meaning of mutant genes, mixing human and animal genes, and (most interestingly) the audience's fears about governmental misuse of genetic technology. Tomorrow's Children, a movie from 1934 that explores America's experience with forced sterilization, generated a heated discussion about the history of this practice and possible presence of eugenics in today's society through prenatal testing. Genetic Journey, a documentary about three people who agree to ancestry testing through DNA attracted a largely African-American audience and inspired a spirited discussion of identity and race with Karla Holloway of Duke and Vence Bonham of NHGRI. A reading list of genetics oriented fiction and non-fiction was generated by the library staff and a special pamphlet was developed for display to help direct reading in the area of genetics. All of our handouts and readings and information about the final Forum were located in the lobby of the Library for eight months leading up to the Forum. The film series was not always well attended. We had chosen Saturday afternoon but a weekday early evening may have been a better choice. Nevertheless, the marketing that resulted from the Film Series was invaluable to the final Forum. The appendix contains much of the material we produced for this series. Following is a list of the films that were shown with themes and moderators:

[Frankenstein](#)- Priscilla Wald, Duke

Science vs. Religion

What makes a monster a monster?

The place of science/scientists in the cultural imagination

Role of the scientist in society

Cloning

Can science play god?

[Lilo and Stitch](#)- Barbra Rothschild, UNC

Attended by children – discussed “What are Genes?”

[Tomorrow's Children](#)- Matthew DeCamp, Duke

Social and legal challenges of eugenics

History and future of eugenics

Race and eugenics

Individual control over one's genetic makeup

Eugenics history in NC

[The Madness of King George](#)- Muge Calikoglu, UNC, and Michael McVaugh, UNC

The nature of recessive genetic disorders

Privacy issues and genetics

Genetics in the workplace

[Spiderman](#)- James Evans, UNC, and Nancy King, UNC

Basic Genetics

Mutations

Animal and Human Genetics

Science, Trust and the Government

[Minority Report](#)- Suzanne Haga, Duke

Genetics and Determinism

Behavioral Genetics

Pharmacogenetics

[Motherland: A Genetic Journey](#)- Karla Holloway, Duke and Vence Bonham, NHGRI

Ancestry Testing

Race, Ethnicity, and Genetics

Y Chromosome

[Gattaca](#)- Arlene Davis, UNC

Genetics and Determinism

Prenatal Testing

Government, Policy, Privacy and Genetics

Community Conversations

We designed the community conversations to be a method of reaching specific communities in an intimate and comfortable way. We secondarily used the topics of interest gleaned from the more informal community conversations to design our main Community Genetics Forum topic, “The Human Genome and Being Human: A Community Conversation on Our DNA, Health, Values and Heritage” and our breakout sessions for the main Forum. Here is an excerpt from a handout we used to advertise a community conversation experience:

Community Genetics Forum 2006

Is your community interested in genetics? For example, can genetic technology help me stay healthier? How accurate is the DNA testing used by police? Is there a ‘violence gene’ or a ‘happiness gene’? Would you like an opportunity to tell your government what concerns you and what excites you about genetic testing and research? The Community Genetics Forum 2006 is your chance!

Community Conversations about Genetics

A series of informal Community Conversations involving a range of communities and groups will address questions and concerns about genetic information and genetic research, and provide an opportunity for learning and discussion. Conversations will begin from a suggested topic of interest, but can be wide-ranging. Scientists and humanities scholars will take part, be available to answer questions from community participants, and help to identify community opinions, interests, and possible needs for follow-up. Conversations are anticipated to last about an hour, and can take any form or direction that the participants desire.

We identified a community partner for each conversation. This was someone who could advise us on all aspects of the conversation, ensure appropriate marketing strategies and help with recruitment. This project is very difficult to explain succinctly to anyone not already familiar with the National Human Genome Research Institute and their reasons for community outreach and education. Our first challenge was to find a community representative with an openness to genetics as a topic of importance to their community. Since community leaders are often asked to bring topics and issues to their community, we needed to quickly present reasons that this topic would be useful, helpful, and interesting to their community. One tactic we used was to emphasize that this was a unique and unusual opportunity to have the ear of the federal government, the body that spends your tax dollars and directs the research priorities, and let them know your preferences, opinions, and thoughts. This seemed to be the most effective explanation. People are reticent to be 'educated' about genetics formally – few people want to spend their free time in a science class. People are also wary of an opportunity to express their opinion if it comes across as an opportunity to criticize their opinion. We tried to make it very clear that these conversations were open and judgment free and that we would provide scientific information insofar as it was asked for and as it would help explain the issues at hand.

Each community conversation was planned in conjunction with our host and partner. We were very concerned with choosing an optimal place and time in order to maximize the comfort level of the invited guests and to maximize attendance. For example, we conducted our conversations with high school students without teachers or parents in the room. We scheduled our conversation with moms at the elementary school after school drop-off in the morning. The following is a summary of each community conversation. A copy of our notetaking form may be found in Appendix A.

This process was very helpful in planning the Forum. It was clear from the conversations that there was a desire for accessible and comprehensible genetics. Our community is interested in the direct impact of genetic technology on their health. They are excited about the possibility of novel interventions for common health problems like diabetes and heart disease. They are concerned about the expense of genetic technology. Many people have reservations about some of the paths genetics may lead us to, for example, an increase in pregnancy terminations due to genetic testing. During conversations with the more religious segments of our community, some of the 'testing' of genetics was felt to be best left to God. Obviously this is a diverse set of needs and attempting to plan in response to these was difficult but rewarding. Following are summaries of each community conversation.

Event Title: Montessori Alumni Day

Date, Time & Location: Friday, May 12, 9:30 am, Montessori Day School, Chapel Hill, NC

Discussion Leaders: Arlene Davis, Amanda Nave, Kristin Meyer

Purpose: A community conversation was held at Montessori Alumni Day in order to introduce the Community Genetics Forum project and to evaluate feedback about the event and proposed topics. Analysis will be used to shape the Community Colloquium held on Saturday, September 16th.

Background Information: Montessori Day School is a private school for Chapel Hill students' grades pre-K – 6th. Montessori is an alternative education system and generally attracts middle- upper class families from diverse backgrounds.

Demographics: (n= 36)

Race:	(30) Caucasian
	(1) Latino
	(2) African American
	(1) Asian American
	(2) Other
Sex:	(21) Female
	(15) Male
Age:	(33) 6-15
	(2) 35-45
	(1) 45-60

Analysis: Major interests among the students were: defining family, ancestry testing, behavioral genetics and the technology for altering genes.

Feedback from Audience:

Number of surveys: 30 * Not all sections were filled in by each individual

Evaluation:

Excellent	(13)
Good	(13)
Fair	(1)
Poor	(1)

Main Interests:

Human Genome	(6)
ELSI Issues	(9)
Both	(14)
Other	()

Most valuable:

Behavioral genetics- talents and characteristics	(7)
Ancestry and Family	(7)
Privacy	(1)
Forensics	(2)
Designer Babies	(1)

Issues to cover/have more coverage in the future:

Cloning
Behavioral Genetics
Forensics
Family Science (understanding genetic relationships in families)
Genetic Engineering
Healthcare companies interests and implications

Aftermath: Amanda Nave returned to the Montessori school on June 15th to teach the students how to extract plant DNA and to follow up on questions about modern technology and genes.

Jewish Women Lerner Day School Moms

The target audience was Jewish women in the Triangle area. This is a community that often does a lot of education about genetic issues already because of the number of single gene mutation diseases that run in the Ashkenazi and Sephardic communities.

Event Title: Sandra E. Lerner Jewish Community Day School Community Conversation

Date, Time & Location: Friday, May 12, 11:00 am, Lerner Jewish Community Day School, Durham, NC

Discussion Leaders: Barbra Rothschild

Purpose: A community conversation was held at the Lerner Jewish Day School with a group of mothers.

Background Information: The Lerner Jewish Day School is for Jewish children in the Chapel Hill/Durham community from pre-school – grade 5.

Demographics: (n= 8)

Race: (7) Caucasian
(1) Other

Sex: (8) Female
(0) Male

Age: (2) 22-35
(5) 35-45
(1) 45-60

Analysis: Major interests among the women were: identity and genes, ancestry testing, behavioral genetics, designer babies and privacy issues.

High School Students

We held a series of community conversations with high school students from across North Carolina at the North Carolina School of Science and Mathematics. Because the final Forum would take place on this school's campus we felt it was especially important to get a sense of the genetic interests of these students.

Event Title:	North Carolina School of Science and Math
Date, Time & Location:	Friday, May 12, Class 1, NCSSM, Durham, NC
Discussion Leaders:	Nancy King, Barbra Rothschild
Purpose:	Multiple community conversations were held at the North Carolina School of Science and Mathematics.
Background Information:	The North Carolina School of Science and Mathematics is a public boarding school where admission is competitive. Criteria include talent and interest in science and mathematics. There is also a state mandate to represent the population of North Carolina both geographically and racially as closely as possible.
Demographics:	(n= 21)
Race:	(17) Caucasian (0) Latino (2) AA (0) Asian American (2) Other
Sex:	(6) Female (15) Male
Age:	(21) 15-18

Feedback from Audience:

Number of surveys: 21 * Not all sections were filled in by each individual

Evaluation:

Excellent	(12)
Good	(7)
Fair	(1)
Poor	(0)

Main Interests:

Human Genome	(5)
ELSI Issues	(1)
Both	(15)
Other	()

Most valuable:

Future technology of genetics	(7)
Designer Babies/genetic enhancement	(4)
Predisposition/Behavioral Genetics	(5)

Issues to cover/have more coverage in the future:

Cloning
Genetic Mutation
Current genetic discoveries/law enforcement
Evolution

Event Title: North Carolina School of Science and Math
Date, Time & Location: Friday, May 12, Class 3, NCSSM, Durham, NC
Discussion Leaders: Nancy King, Barbra Rothschild, Kristin Meyer
Demographics: (n = 20)

Race:	(18)	Caucasian
	(0)	Latino
	(1)	African-American
	(0)	Asian-American
	(1)	Other
Sex:	(7)	Female
	(13)	Male
Age:	(20)	15-18

Feedback from Audience:

Number of surveys: 20 * Not all sections were filled in by each individual

Evaluation:

Excellent	(12)
Good	(7)
Fair	(1)
Poor	(0)

Most valuable:

Application of genetics to further research	(1)
Designer Babies/genetic enhancement	(7)
Ethics and Societal Impact	(10)
Ancestry Testing	(1)

Issues to cover/have more coverage in the future:

- Cloning
- Genetic Therapy
- Evolution vs. Mother Nature
- Current genetic discoveries/ law enforcement

Minority College Students

Event Title: Duke University Summer Medical Education Program (SMEP)

Date, Time & Location: Wednesday, July 12, 12:30 pm, Duke University, Durham, NC

Discussion Leaders: Barbra Rothschild, Nancy King

Purpose: A community conversation was held at Duke University with the Summer Medical Education Program. The event was scheduled by Nikki Vangsnes of Duke University. It took place over lunch in a large lecture hall.

Background Information: The SMEP is described thus: “The summer program at Duke University offers talented students the resources to present strong credentials for admission to medical school. By providing a solid foundation in the pre-medical sciences, math, writing, and learning skills, the program prepares its scholars for success. Instruction in ethics, professionalism, interviewing skills, clinical experience, and individual advising complete the toolbox. Program scholars will leave well prepared to complete their undergraduate education and advance to health-professions education.” This talk was given as part of a 6 week program of scientific research enrichment.

Demographics: (n=approx. 60)

Race: (8) Caucasian
(7) Latino
(35) African-American
(5) Asian- American
(5) Other

Sex: (30) Female
(30) Male

Analysis: A case of a young adopted man raised as white who then undergoes ancestry testing started the conversation. This case started a lively discussion of race, identity and culture issues. There was a divide between those who thought that

one's DNA should have an effect on policy issues (like scholarships) and those who did not. There was interest in how ancestry testing works, how accurate the testing is, and what its implications are for the future. Towards the end of the discussion, the issue of prenatal testing and 'choosing' traits was brought up by the audience.

Feedback from Audience:

Number of surveys: 49 * Not all sections were filled in by each individual

Evaluation:

Excellent	(18)
Good	(28)
Fair	(3)
Poor	(0)

Most valuable:

Race and Genetics Discussion	(21)
Scenarios/Cases	(9)
Ethics and Science	(5)
Ancestry	(4)
Genetic Science	(2)
Nature vs. Nurture	(2)
Privacy	(2)
Discussion of what NIH is	(1)
Social Policies	(1)
Discrimination	(1)

Issues to cover/have more coverage in the future:

More specific genetic science

Ancestry

Policy and Genetic Research

Human Genome and Race

Sexual Orientation and Genes

Behavioral Genetics

Stem Cell

Criminal Justice System and Genes

Personal Responsibility

Prenatal Testing

Genes and the Environment

White Rock Baptist Church

- Event Title:** White Rock Baptist Church Community Conversation
- Date, Time & Location:** Saturday, August 12, 9 am, White Rock Baptist Church, Durham, NC
- Discussion Leaders:** Vence Bonham, Goldie Byrd, Barbra Rothschild
- Purpose:** A community conversation was held at White Rock Baptist Church with a Christian Education Group that meets regularly on Saturdays.
- Background Information:** Dr. Goldie Byrd, the Chairwoman of Biology at North Carolina A & T, and a member of White Rock Baptist Church scheduled this Community Conversation. The Conversation became part of a Christian Education class that she teaches regularly on Saturdays.
- White Rock Baptist Church is one of the first African-American churches in the Durham area. It was founded in 1866 and has served the community continuously since then. It is part of the Progressive National Baptist Convention.
- Demographics:** (n= approx 8)
- Race:
 - (0) Caucasian
 - (0) Latino
 - (8) African-American
 - (0) Asian- American
 - (0) Other
 - Sex:
 - (8) Female
 - (0) Male
 - Age:
 - (3) 35-45
 - (5) 45-60

Analysis:

We began with an explanation of the Community Genetics Forum and then opened the floor for comments. We asked them what came to mind when hearing the word “genetics”. One woman started by telling a story. She had been to an education conference where a study was presented that implied that black children are inherently more prone to behavior problems than white children. She said that this made her angry and that she felt that there must be some fundamental problems with this type of study but she didn’t feel comfortable enough with her knowledge of genetics to refute the findings. The discussion then shifted to the meaning of race, the social meaning of race, and its relationship to one’s genes.

Most of the conversation and questions dealt with issues of health and genetics and health in general. There was much discussion of diet and weight, including a long and fruitful exchange on how to conduct effective outreach efforts to help church members change their diet, exercise more, and lose weight. We discussed genetic factors for weight gain and the chronic diseases that plague the African American community, e.g. diabetes, hypertension, and heart disease. We spoke of the social factors that affect health. There was a discussion of the kinds of doctors that these women felt most comfortable with and how race played into the doctor/ patient relationship.

Questions about genetics and diabetes and heart disease were answered and suggestions for further information were given to the group as well as information packets that were left at the church for those that were unable to attend.

Aftermath:

Some of the women that attended this community conversation attended the main Community Genetics Forum in September. Our connection with Dr. Byrd continues. She is an external advisor on a Center of Excellence on ELSI research grant application.

Latino Community

The Latino community in the Raleigh-Durham area is a rapidly growing immigrant population. Because of the extremely low unemployment in the area, Latino workers are drawn here by the employment availability primarily in agriculture, construction and service jobs. From the beginning we anticipated that this might be a difficult audience to reach because of language barriers and time priority issues. We hired a Latina health educator with previous experience in the area of diabetes education outreach for this community. We developed a plan of outreach that included advertisements in the Latino newspapers and on the local Spanish-speaking channel. We also developed a basic genetics education presentation in Spanish to introduce our conversation. We then contacted a Catholic Church that serves a portion of our rural latino community. We had extensive talks with the priest who serves that congregation about the types of issues we might be addressing. While we said we would purposefully bring up issues of preconception/prenatal genetic manipulation/testing/termination, we would answer any questions that were asked of us in as truthful and unbiased way as we could. We emphasized that our intent was really some basic genetics education and then a feedback session for any concerns about genetic issues that might be in the community. The priest agreed to these terms. He became enthusiastic about the project and announced the day and time of our conversation at Mass for a few weeks. We also advertised in the church newsletter. We scheduled the conversation for a weekday morning from 10-12 on the advice of our hosts. We did not have anyone show up to the community conversation. In retrospect, the priest felt that perhaps scheduling it right after Mass on a Sunday might have worked more effectively. In general it was felt that this community is financially stressed and asking them to find babysitters or spend non-working hours discussing genetics is very difficult. We discussed ways of presenting the relevance but for this community at this time it just was not an option.

Event Title: Ideas! Coffee House presents: “Am I my Genes?” Race, Genes and Ancestry in Today’s World

Date, Time & Location: Saturday, July 1, 12:00 – 1:30, Ideas! Coffee House, Durham, NC

Discussion Leaders: Nancy King, Rebecca Walker, Shuba, Rene Sterling

Purpose: A community conversation was held at the Ideas! Coffee House in order to engage a diverse audience in discussion on race and identity. Analysis will be used to shape the Community Colloquium held on Saturday, September 16th.

Background Information: The Ideas! Coffee House is owned and managed by two African American brothers who attended NC Central. The general area surrounding the coffee house is extremely diverse and the coffee house clientele tends to be mostly African American.

Demographics: (n= 10)

Race:	(5) Caucasian
	(1) Latino
	(3) African- American
	(1) Asian -American
Sex:	(8) Female
	(2) Male
Age:	(3) 22-35
	(4) 35-45
	(3) 45-60

Analysis: Major interests among the group were: cultural and personal identity/race, ancestry testing, behavioral genetics, and privacy issues.

Forum Events

When we began the planning in January for the Community Genetic Forum, we realized we had two tracks of planning. One was the ongoing track of the smaller events that would occur throughout the year and inform the content of the main events. The other track was the planning for the large events in the fall. Both tracks needed continuous attention. This section of the report is concerned with the second track - the planning and implementation of the Community Genetic Forum 2006 fall events. We planned three days of events for the fall. The first day was primarily concerned with policy. We then planned two full forums, one directed at the academic community with a more conceptual grounding, the other directed at our 'neighborhoods' community responding to the questions and concerns raised at the community conversations.

Space Considerations

An initial challenge was finding appropriate space. Some questions we asked ourselves were:

- What are the events?
- What technology will the events require?
- How many attendees do we expect?
- How will they get to the event?
- If needed, where will they park?
- Will weather make a difference in the venue?
- Is the venue ADA compliant?
- Can we have food at the venue and are there restrictions?
- Can we set up extra tables etc.?
- Is the venue accustomed to this type of event?
- What is the administrative assistance like?

We wanted event spaces that felt central and accessible to our audience with plenty of public transportation access and parking. Because we anticipated breakout sessions we needed smaller rooms nearby. Room size was very important. Certainly we needed enough room but a room that is too large can affect the way the event is experienced by the participants in

a negative way. For Friday's event, Finding the Genome, this was a very difficult task. We needed a room that could accommodate three hundred people on campus in the middle of an academic school day. We felt if we held the forum at one of the off-campus conference sites we would lose significant audience. We arranged for the use of a large lecture hall for 600 students but we knew to expect 200 medical students as a baseline. There is also a nearby parking deck for public use. Saturday's event, The Human Genome and Being Human, was more straightforward. From the beginning we had in mind the North Carolina School of Science and Mathematics, a public boarding school that occupies a former hospital in the middle of Durham. Because we chose Saturday for this event, there would not be any classes, so students would be free to come. The community is very familiar with the school and its urban location. Public transportation is available there as well as food services. The auditorium is relatively new so the technology is recent and able. A last comment on space was the Nurses CME that was held on Thursday. This event made sense at an outside conference center because it was designed to attract nurses from across the state. The center is very familiar with CME courses and that made the planning much easier.

Website, Logo, and Marketing

From early on in the process we felt that it was important to mount a running, current website with an identifiable logo that could be used on all of our marketing materials, correspondence etc. When trying to encourage the general public to invest time and trust in a project such as this, we needed to be easy identifiable and our information easily found. We hired a graphic designer to develop a logo for us. We wanted something clean and symbolic, but not too abstract. We wanted something that was not tied to NC so it could be used for future forums and possibly serve as a tie from year to year, increasing the visibility and familiarity of the Forum in the public's eye. We did not want the logo tied to race or ethnicity or limited to the science of genetics. We wanted to include the concept of community if possible. The logo was used as a unifying image on all our printed and web material. The website was the another key part of our early marketing strategy (<http://genomics.unc.edu/cgf/>). We organized the website so that the events through the year could be viewed. The Forum was highlighted and connected to the other events such as community conversations and the film series. We had our sign-up for both days of the Forum through this website. As a group we acknowledged that web-based sign-in was not ideal for the general public but we made clear on our marketing materials that it was not essential for attendance.

We kept a running log of marketing opportunities for each event. For example, for Saturday's forum we kept a list of listservs that had been offered to us to notify the public of the event. Organizations such as the North Carolina Association for Biomedical Research, the ARC of North Carolina, Office of Community Affairs at Duke University and the Durham County Library, and the North Carolina Museum of Life and Science were all willing to post a notice on their listservs about Saturday forum with Francis Collins and many posted a notice on their own website. We also had an official press release that was produced and distributed through the University's press office. We contacted local newspaper reporters who cover the science and technology news so giving them sufficient notice to attend the event. We arranged for Dr. Collins to speak on a local noontime radio show, State of Things, and take questions with a local geneticist about two weeks prior to the Forum. This was very successful in getting the word out as it also ensured the public radio website would post a reminder about the event. We went to community events and passed out Save the Date Cards. We had posters about the events at local grocery stores, churches, community boards, senior centers and other places used for notification open events. These methods were most successful at increasing awareness and curiosity about genetics in our community and encouraging sustained interest in developing new genetic education projects.

Institutional (UNC) Support

Some of our first meetings for this project were scheduled with University administration whose support we felt was essential for the success of the Forum.

Community Genetics Forum: Policy Roundtable

From the beginning this was an important aspect of the project. Encouraging the community to consider issues in genetics is reflected in doing the same with their elected officials and government policy makers. Ideally we wanted to have a 'conversation' or interplay between the community, policy makers/influencers, and genetic scientists. This way both the concerns of the community and the needs of the scientist could be heard by policy makers. It would also give the community and policymakers a chance to ask prominent geneticists for clarification on scientific issues they may be concerned or confused about.

We developed the guest list with the assistance of the Dean's office, the Vice-Chancellor for Research, and a faculty member from our Institute of Government who was very familiar with the landscape of North Carolina State Government. We invited all of the State Legislators with a seat on a science, health, or technology subcommittee. We also invited our local representatives who were members of the state government in health related fields such as

the director of the Office of Minority Health and Health Disparities. We invited representatives from health care lobbying groups in our area and representatives from pharmaceutical and the biotechnology industries. We invited the CEO of the largest health insurer in our state. We felt fortunate to have an incredibly knowledgeable and diverse mix of attendees who were enthusiastic about the round table.

We then performed an assessment for policy topics. We held some focus interviews with our community contacts and the partners that we had identified early on. These partners included the North Carolina Biotechnology Center, the Program on Ethnicity, Culture, and Health Outcomes, administrators in the School of Medicine and some legislative aids in the North Carolina State Legislature. We came up with a short list of topics. The first was intellectual property issues as our community is the third largest biotechnology industry center in the United States and this is of great concern to that community. The second was the rising popularity of DNA banks. North Carolina has had some state DNA banks proposed to the State Legislature, based on newborn blood spots to be used both for the criminal justice system and for research. This was hotly debated in the North Carolina House and although not passed was felt to be a question on the mind of some legislators. The third policy issue was the proposed genetic non-discrimination bill at the national level and its relationship to the non-discrimination policy already in place in North Carolina. This topic extended into issues of genetic privacy especially with regard to employment and insurance. We sent this list of topics with ‘cases’ to help people understand their scope and asked them to get back to us with their priorities for discussion. The feedback suggested that the non-discrimination bill and the privacy issue were on the minds of our guests and they were all looking forward to discussing them with Dr. Collins.

The policy roundtable was a great success for us, the attendees, and the University. The conversation was active but respectful. Attendees were clearly interested in hearing from Dr. Collins and others around the table that they hadn’t met before. We were able to connect those with expertise and knowledge in this area with legislators and aides in productive and helpful way.

**Friday’s Event: Find the Genome:
Group Interests in Genetic Testing and Research**

As a P20 project, members of our ELSI group, Rebecca Walker and Nancy King set out to consider whether “scale-up” presented novel ELSI issues; this research was intended to provide conceptual foundations for the empirical work of the rest of the planning group, and to

facilitate connections between theory and practice in addressing ELSI questions. With the help of a research assistant, they began examining the genetic biobanking literature and related literature, focusing primarily on conceptual, philosophical, and policy writings rather than strictly empirical research.

The first product of this work was an extensive annotated bibliography and accompanying “library” of literature addressing a range of topics relevant to genetic research and biobanking, including the debate about informed consent, ownership and control of biospecimens, privacy and confidentiality, and group interests. They identified the principal tensions and debates in the literature on each of these issues, all of which speak to the larger tension between the prerogatives of progress in genetic research and the interests and needs of individuals and groups, whether healthy or affected by genetic disease.

This product contributed significantly to the development of plans for a uniquely themed academic colloquium on group interests in genetic research, to address considerations that go beyond individual decisionmaking and raise questions about group stigma, community consultation, and the impact of genetic knowledge on cultural narratives. The colloquium was planned to address the questions: What are groups? Why are (or aren't) groups useful in genetic research? What are the consequences of using groups in genetic research? And who should oversee genetic research with groups , and how?

The overall colloquium plan became the core model for the Community Genetics Forum, “Finding the Genome”. The questions identified in the literature informed the film series discussions and the “community conversations” held before both conference days, and the topics identified helped to shape the conference presentations, panels, and especially the concurrent sessions, including training materials for concurrent session leaders.

We took the idea developed by Walker and King and gave thought to what panel of speakers might complement Dr. Collins’s perspective on this topic. We believed a balanced and respectful discussion of the questions listed above would be an incredible educational experience for both our campus and neighboring North Carolina academic institutions. We asked Dena Davis, a Professor at Cleveland-Marshall College of Law, and author of *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children’s Futures* and Debra Harry, Executive Director of the Indigenous Peoples Council on Biocolonialism (IPCB) to complete our speaker roster. We believed this group would also be effective in speaking to the public the next day at our community event.

As described earlier we developed parallel tracks for the three days. Invitees and others would be following different schedules based on their interests. We developed separate schedules and events for undergraduate students from the HBCUs who were visiting us and for graduate students from area academic institutions (see below).

HBCU Undergraduate Program

As described earlier, we devised several ways in which the larger North Carolina academic community could participate in Finding the Genome. One very successful effort was the partnership with SPIRE to bring in undergraduates interested in pursuing a career in science to the University of North Carolina for an overnight program with Dr. Collins and the other members of NHGRI as well as our own faculty members. The schedule for these students is below.

HBCU Students and Area Undergraduates Welcoming Program

Location: Taylor/Isaac Hall, Room 124, UNC at Chapel Hill

Time: 6:00 pm - 9:00 pm

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

Finding the Genome: Group Interests in Genetic Research and Testing

Date: Friday, September 15

Time: 9:00 am - 3:00 pm

Location: MBRB, Main Auditorium, Health Affairs Campus, UNC at Chapel Hill

9:00	Welcome and Introductions by Dean Roper
9:20	Plenary Lecture: Francis Collins, MD, PhD, Director NHGRI
10:00	Plenary Lecture: Debra Harry, Executive Director, Indigenous Peoples Council on Biocolonialism
10:40	Plenary Lecture: Dena Davis, PhD, JD, Professor of Law, Cleveland-Marshall College of Law

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- 11:15 Panel Q&A/Discussion with speakers, moderated by Jim Evans, MD PhD
- 12:00 Lunch (pick up box lunches)
- 12:45-2:00 Lab Tours, meet in main lobby
- 2:15 Reaction Panel and Wrap-up Discussion, moderated by Jim Evans, MD PhD.
Location: MBRB, Main Auditorium
Panelists: Adam Searing, Diane Baker, Karla Holloway, and Terry Magnuson
- 3:00-4:00 Francis Collins, The Future of Genomic Science
Location: MBRB, Small Auditorium
Participants: HMU visitors and Undergraduates
- 4:30-6:00 Expert Panel Reception
Location: MBRB, Main Lobby
Participants: Graduate Students, Post-Docs and Undergraduates

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

Date: Saturday, September 16
Time: 10:00 am – 3:00 pm
Location: North Carolina School of Science and Mathematics

- 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
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- 11:10 Panel and Town Hall Meeting featuring Community Leaders moderated by Jim Evans, MD PhD
- 12:00 Lunch (pick up box lunches)
- 1:00 Concurrent Breakout Sessions:

Graduate Students

We developed events for graduate students designed to attract minority students to genetics and to answer career questions for all of our visiting students. Their schedule appears below:

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

Location: Health Sciences Library, Room 527, UNC at Chapel Hill

Time: 7:30 am - 8:45 am

NHGRI Participants: Francis Collins, Vence Bonham, Milton English, Carla Easter, Laura Rodriguez

Finding the Genome: Group Interests in Genetic Research and Testing

Location: MBRB, Main Auditorium, Health Affairs Campus, UNC at Chapel Hill

Time: 9:00 am - 3:00 pm

- 9:00 Welcome and Introductions by Dean Roper
- 9:20 Plenary Lecture: Francis Collins, MD, PhD , Director National Human Genome Research Institute
- 10:00 Plenary Lecture: Debra Harry, Executive Director, Indigenous Peoples Council on Biocolonialism
- 10:40 Plenary Lecture: Dena Davis, PhD, JD, Professor of Law, Cleveland-Marshall College of Law
- 11:15 Panel Q&A/Discussion with Speakers, Moderated by Jim Evans, MD PhD

12:00-1:00	Francis Collins, The Future of Genomic Science <i>Location: Lineberger Cancer Center, Plaza Room</i> <i>Participants: Graduate Students and Post-Docs</i>
1:00	Concurrent Breakout Sessions:
3:00-4:30	NHGRI Expert Panel <i>Location: MBRB, Small Auditorium</i> <i>Participants: Graduate Students and Post-Docs</i> 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 <i>Participants: Graduate Students, Post-Docs and Undergraduates</i>

To prepare the breakout sessions, we made use of the aforementioned annotated bibliography by designing sessions around particular themes, questions, and readings. We began with the “group interests” overall theme to shape the UNC colloquium. For the more community-oriented NCSSM colloquium, we repeated some sessions, but also added a number of new sessions that went beyond the scope of group interests but appealed to the general public, based on what we had learned through the community conversations.

We adapted the Community Conversations Facilitators Guide for breakout session leaders at both the UNC and the NCSSM events. We also prepared handouts specific to each breakout session, circulated them in advance to session leaders for their input and possible amendment, and copied the final choices for on-site distribution.

Friday September 15 Colloquium Concurrent Sessions

But race isn't genetic, is it...?

Vivian Ota Wang, Giselle Corbie-Smith

This session critically examines the concept of race from genetic, social science, and humanities perspectives. While there is largely agreement among experts that race is not itself genetic, racial categorization is ubiquitous in biomedical research and in clinical care. This session will examine the reasons that race categories persist as “proxies” for genetic information that may be useful as well as the potential pitfalls of using these socially constructed categories.

Genetic narratives, group narratives, and the media

Rebecca Kolberg, Felicia Mebane, Joseph Jordan

Using literature and media studies, this session considers how genetics is talked about in public narratives, such as newspaper articles and fiction, and examines how such public narratives both shape and are shaped by society's views of genetics, genetic identity, and stigma. This examination provides the opportunity to understand the ethical and social effects of genetics on how we understand ourselves as members of groups.

Health disparities, genetics, and the rhetoric of responsibility

Gail Henderson, Jay Kaufman

This session critically examines the medical and epidemiological literature and data on genetic explanations for health disparities between groups. This examination provides a framework for discussion of the ethical and policy implications of promoting and not promoting genetic explanations for disparities, including consideration of individual, group, and political responsibilities. Issues of the just distribution of resources are considered in this context.

Groups, genetics, and research oversight

Laura Rodriguez, Nancy King, Lynn Dressler

Possible harms to groups arising from the conduct of genetic research or the publication of its findings fall outside the purview of federal research oversight by IRBs. However, research involving groups, and group interests and harms, are of increasing importance in genetic research, especially in the context of “DNA biobanking.” How can and should researchers, institutions, and funders think about possible group harms? What ethical considerations are relevant, and what oversight mechanisms provide the most effective means of addressing them?

Genes, family, and ancestry

Karla Holloway, Nancy King

Family can be understood in many different ways, but advances in genetic ‘ancestry testing,’ as well as well-established testing for paternity and other close family relationships, delineate these concepts in specific and controversial ways. This session looks at the nuts and bolts of how ancestry testing works and what it can and can’t reveal scientifically. It also addresses the social issue of whether genetics has changed how we understand family relationships and ancestry.

Genetics and Clinical Translation

Eric Green, Chuck Perou, Howard McLeod

This session discusses the possibilities and importance of translating genomic research to the clinic. Before it even gets to the bedside, however, there are decisions to be made on what research will be focused on. This session will discuss current genetic research topics and the ultimate goals and challenges of translation to therapeutics.

The Human Genome and Being Human:

A Community Conversation on our DNA, Health, Values and Heritage

Our main event for the community was designed to reflect what we had learned about our community in the previous six months from Community Conversations and other events. We used the evaluations that we handed out at every event, our own observations, and the data that people gave us on the website as to their preferences of topics. In many ways the logistics for this day were more straightforward and we had the advantage of NCSSM’s staff and student body to help with directions and guiding our guests. We were incredibly fortunate to have joined Duke University to bring the Liz Lerman Dance Exchange as they were performing a piece that they had written after consulting many prominent geneticists including Dr. Collins. A group our NHGRI visitors and our core group attended the Genome performance on Friday night. In turn, representatives from the dance troupe taught a class at The Human Genome in experiencing one’s DNA through body movement. The students requested a breakout session with Eric Green on the latest advances in genetic medicine, and the other breakout sessions were similarly informed by previously described events. We marketed this event through posting flyers in grocery stores, churches, and libraries. We posted announcements on community listservs from Duke University, UNC Hospitals, the ARC (a non-profit serving the mentally disabled and their families), Durham Neighborhood Associations, the Durham

Congregations in Action group, the North Carolina Association for Biomedical Research, the North Carolina Humanities Council, the North Carolina Museum of Life and Science and the North Carolina Biotechnology Center. We spoke about the event at other community events and openings. We also arranged for Dr. Collins to be interviewed on our local public radio station a week before the event. We had a press release and called journalists that we had identified as interested in the sciences. While the task of encouraging people to spend their Saturday talking about genetics is a difficult one, the process is useful and may have accomplished as much in itself.

Saturday September 16 CGF Concurrent Sessions

Ancestry Testing: Understanding our Heritage through DNA

Vivian Ota Wang, Karla Holloway, Joseph Jordan

This session examines the concepts of race and family from genetic, social science, and humanities perspectives. While there is largely agreement among experts that race is not itself genetic, racial categorization is ubiquitous in biomedical research and in clinical care. This session will examine the reasons that race categories persist as “proxies” for genetic information that may be useful as well as the potential pitfalls of using these socially constructed categories. Family can be understood in many different ways, but advances in genetic ‘ancestry testing,’ as well as well-established testing for paternity and other close family relationships, delineate these concepts in specific and controversial ways. This session looks at the nuts and bolts of how ancestry testing works and what it can and can’t reveal scientifically. It also addresses the social issue of whether genetics has changed how we understand family relationships and ancestry.

DNA & Health: The Role of Biomedical Research

Alan Guttmacher, Giselle Corbie-Smith, Terry Magnuson

This session answers questions about the future of genetic research in every day clinical medicine. How could participation in genetic research improve the health of future generations? What areas of medicine are most likely to benefit from genetic research?

Genetic Enhancement & Designer Babies: Can we, should we?

Arlene Davis, Muge Calikoglu

This session addresses the scientific, ethical, and social implications of prenatal and newborn screening and testing for genetic conditions. Topics include proposals to expand screening to add new conditions; screening and testing before babies are born; and screening and testing before they are conceived. What do screening results mean, especially when

treatments are not available? What counts as a “benefit” of screening, and what is a “harm”? What is the difference between rejecting “bad” genes in a baby and choosing “good” genes? Can science do any of this yet? Should society allow it?

Privacy, confidentiality, and DNA identification

Phyllis Frosst, Lauren Dame

Is it possible to maintain privacy in an era of genetic medicine, forensic genetics, and large-scale genetic database research? What kinds of privacy questions are raised by the new genetics, and what kinds of privacy protections are needed? “Forensic” uses of DNA identifies individuals from their DNA, helping to find out who did the crime, who fathered the baby, or the identity of a body. DNA testing of residue at crime scenes has changed the way we perceive the criminal justice system and evidence. Should we have a genetic data-base for all people in the US which could be used for forensic purposes? Should crime scene DNA be used to try to assess the race of a perpetrator?

Genetics, Behavior, & Ethics: What do genes have to do with your personality?

Bob Cook-Deegan, Amy Laura Hall

We already know that social influences and our physical environment contribute a lot to how we behave, what we believe, and what we care about. As we identify the roles of more and more genes, we have started to investigate whether there are genes that help to determine our behavior, preferences, and beliefs as well. Questions raised by this topic include: Are some people disposed to violence through their genetic inheritance? What about sexual preferences or a belief in god? Could your genes influence how kind you are or whether you are courageous? Does identifying genetic associations with personality traits weaken the role and importance of character and values?

The Liz Lerman Dance Exchange Workshop

Liz Lerman leads a dance class on experiencing DNA through body movement.

Forensics and DNA

How will the use of DNA in our criminal justice system affect us in our every day lives. How will we balance privacy with a very powerful tool to clear the innocent? Should we be using databases from the general public to assist our public safety?

DNA Extraction! For Kids and Adults alike!

UNC genetics graduate student Amanda Nave will give a demonstration on extracting DNA from common plants with everyday materials. You could do it at home!

What's New and Exciting in Genomics Research!?!? For NCSSM students

Dr. Eric Green, a leading genetics researcher, talks to NCSSM students about the latest advances and opportunities in genetic science.

Film Series and Community Conversation Feedback Forms

Assessment tools were developed to assist both in the planning and evaluation of Community Genetics Forum (CGF) 2006 activities. The core groups had discussions amongst themselves and with NHGRI as to what outcomes were most important to future Community Genetics Forums. We kept narrowly focused on assessing the success of marketing as reflected by attendance of target populations. We were also interested in assessing overall marketing techniques as well as our strategy to choose topics of interest to the community. Because of our approach of 'rolling' events, like the community conversations, we were able to approach evaluation the same way. We reviewed our evaluations after each event in order to modify the next event to reflect the feedback. This was felt to be very effective.

As described in earlier sections of this report, a film series, *Finding the Genome: Fact and Fantasy* was developed in conjunction with the Durham County Public Library to help acquaint the local community with the variety of medical and ethical issues in genomics and to generate interest in attending the day long community forum in the fall of 2006. Following the showing of each film, filmgoers completed a form with a short set of questions designed to assess the value of the program, learn about participants' interests in attending the event, and whether they would be interested in attending other CGF events. In addition, the form included questions about topics individuals would like to see addressed in future forums and how they heard about the series.

A slightly modified version of the feedback form was also used to gather information from the *Community Conversations* held in a number of locations in Durham and Chapel Hill, North Carolina prior to the fall community forum. Responses to the questions helped planners as they considered topics for breakout sessions for the fall day-long community forum and provided information on where and how to promote the forum. Data from the feedback forms appears below.

Friday Conference Evaluation

Because many of the participants of the Friday Conference, Finding the Genome, Group Interests in Genetic Testing and Research, were from area colleges and Universities, we were able to use an online evaluation tool which had a very good response rate. We generated

a separate evaluation tool for the students from the HBCUs because we wanted to ask about accommodations and more specific questions about the special program we had designed for them.

Demographic Information Form

Demographic information about participants was collected at the Saturday, September 16, 2006 day-long Community Genetics Forum: *The Human Genome and Being Human*. A form was designed together with staff from NHGRI to collect information about age, gender, race, and work/school status of individuals who attended the forum. Participants were asked to complete the short form upon arrival

Community Forum Evaluation

Participants at the Saturday, September 16th forum were provided an evaluation form in their information packets which they were asked to complete at the end of the day. It included questions about the overall value of the forum, what they had learned, if they felt they had enough opportunity to ask questions and if they were adequately answered. Students for whom we had an email address were surveyed via an online survey service. The response to this approach was excellent.

Session Summaries

Note-takers were assigned to each breakout session at the September 16th forum so that planners would have a summary of each presentation and the questions that came up during the session. The note-takers were provided a Note-taker's Guide which asked them to describe the session content, characteristics of the group, the views and questions expressed and group dynamics. A similar set of guidelines designed by planners of the University of Washington Community Genetics Forum provided an excellent model. Good notes were taken by the note-takers, however, the consistency was less than we had hoped.

Final Thoughts and Continuing Effects

The Community Genetics Forum has had long reaching effects on our community and the University of North Carolina at Chapel Hill. The goal of the forum was not limited to expanding the conversation about genetic science in one year alone but to plant the seeds of discussion for years to come. These seeds were planted in many ways. Long-term collaboration efforts with community groups were established to continue education about genetics in the community. Graduate students were inspired to consider community outreach as a valuable and necessary aspect of their career. Mentor and mentoree and collaborative relationships were started and solidified with Historically Black Colleges and Universities in our state. An increased familiarity with the NHGRI staff has led to increased knowledge of training opportunities for our areas students at every level. The ripple effect continues; we describe some specific cases below.

University of North Carolina DNA Day Model

In 2007 the University of North Carolina at Chapel Hill served as a model to pilot a DNA Day outreach program where graduate students and postdoctoral fellows in the biomedical sciences acted as DNA Day ambassadors. One of the coordinators was inspired by her involvement with the Community Genetics Forum outreach and education activities and used the Forum as a way to increase her skills in these areas. The administrator who spearheaded this effort was an early and enthusiastic partner of the Community Genetics Forum and helped shape the graduate student outreach efforts. Here are some quotes from the graduate students who participated in DNA Day.

“Our genetics are going to play an important role in the future on many different levels, including health care. It is crucial for students to have an understanding of what the human genome is and the ethical implications of its use beyond just the biology of DNA. I am very excited to share some “real life” applications of biology with students and hopefully inspire a new appreciation for science in the process.”

Elizabeth Sweger, UNC-Chapel Hill Graduate Student

“Many students think of scientists as old men in lab coats. Hopefully, we’ll abolish their stereotypes and leave them thinking that science is really cool and inspiring. My hope is that our program will motivate a whole new generation of scientists.”

Jessica Harell, UNC-Chapel Hill Graduate Student

“I think DNA Day is a wonderful opportunity to not only discuss aspects and implications of the genome project, but also to demystify the image of a scientist. We can show these students that we are not crazy people walking around with wild hair with beakers containing colored bubbling liquid that is about to explode, but that we are people who truly want to make a difference to help society, and hopefully, encourage some of them to join the cause. I am honored to be a part of DNA Day.”

Michael Johnson, UNC-Chapel Hill Graduate Student

Mentorship and Collaboration with North Carolina Central University

We are collaborating with Kimberly Cogdell, Law faculty at North Carolina Central University (NCCU is one of North Carolina’s Historically Black Colleges and Universities or HBCUs), on her training and research program that includes: 1) incorporating ELSI issues into the existing Bioethics Law course at NCCU School of Law; 2) mentoring by P20 investigators in scholarly writing and grant writing; 3) developing an “Introduction to ELSI Seminar” in collaboration with the Biotechnology and Pharmaceutical Law Institute at NCCU School of Law; and 4) cross-CEER training through spending a week at the Center for Genetic Research Ethics and Law (CGREAL) at the Case Western Reserve University. Professor Cogdell and the ELSI group at the University of North Carolina established their relationship through the Community Genetics Forum.

Durham County Library

Our film series collaboration with the Durham County Library was viewed with great success. The library has leveraged the Series to apply for more funding to do other science education programming on our community. They have also partnered with the North Carolina Museum of Life and Science, another Community Genetics Forum partner, to apply for funding for a joint genetics exhibit and educational series for kids. They have asked one of our team to serve on their Board in part to assist in this process.

P50 ELSI Application

The P20 ELSI team that was instrumental in developing and implementing the Community Genetics Forum strengthened their ties to the University community in the sciences and social sciences through this endeavor. The Chairman of the Department of Genetics was committed to the project and attended every event. In turn his support of the P50 application was amplified

and his support of events like the Policy Roundtable also became clear. Third parties have now commented very favorably on the interdisciplinary strength of our ELSI team; we attribute that in large part to the unifying experience of the Community Genetics Forum. Our choices for an External Advisory Board for the P50 was also heavily influenced by our experience with the CGF. We have included community representation and Dr. Goldie Byrd, the Chair of Biology at North Carolina A & T, someone we were unfamiliar with prior to the Forum but whose expertise and enthusiasm for genetics education and community outreach was so helpful and inspiring.

Policy Roundtable Series

The CGF Policy Roundtable has become a model for future roundtable on science and policy at the University of North Carolina. The positive experience and feedback has encouraged the administration to support further Roundtables with an emphasis on diverse opinions and community involvement.

North Carolina School of Science and Mathematics

We are in the early stages of planning collaborations with NIH training section and North Carolina High School Students, a partnership that could not have happened without the relationship building effect of the Forum.

These are but a few of the ongoing and multiplying effects of the CGF on the North Carolina Community.