

## **Addendum: Survey Results**



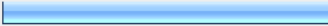
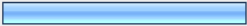

## Addendum: Survey Results from Friday Participants of the CGF

At least 600 people attended the Friday talks with Francis Collins, Debra Harry, and Dena Davis, but not all participants signed in. Those who did sign in, and also provided an email address, were invited to fill out an on-line evaluation survey using SurveyMonkey.com. The following tables were created using the reporting tools on SurveyMonkey.com.

1. Which Community Genetics Forum events did you attend? (please choose all that apply)		
	Response Percent	Response Count
Graduate Minority Breakfast in HSL	1.4%	1
<b>Plenary Lectures (Dr. Collins, Dr. Harry &amp; Dr. Davis) in MBRB</b>	<b>98.6%</b>	<b>70</b>
Graduate lunch with Dr. Collins in Lineberger	32.4%	23
Breakout Sessions	45.1%	32
Reaction Panel and Wrap-up Discussion in MBRB	38.0%	27
Graduate Expert Career Panel	19.7%	14
Graduate and Undergraduate Reception	18.3%	13
Other (please specify)	2.8%	2
	<b>answered question</b>	<b>71</b>
	<b>skipped question</b>	<b>0</b>

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

4. Please rate the following activities. If you did not attend a particular event, please choose N/A.					
	Excellent	Good	Fair	Poor	Response Count
Minority Breakfast in HSL	1.9% (1)	0.0% (0)	0.0% (0)	0.0% (0)	53
Plenary Lectures	61.4% (43)	34.3% (24)	2.9% (2)	0.0% (0)	70
Graduate Lunch with Dr. Collins in Lineberger	23.7% (14)	11.9% (7)	3.4% (2)	0.0% (0)	59
Breakout Sessions	19.0% (11)	19.0% (11)	15.5% (9)	0.0% (0)	58
Reaction Panel and Wrap-up Discussion in MBRB	25.9% (15)	10.3% (6)	10.3% (6)	0.0% (0)	58
Graduate Expert Career Panel	18.2% (10)	7.3% (4)	1.8% (1)	0.0% (0)	55
Graduate Expert Reception	13.2% (7)	7.5% (4)	0.0% (0)	0.0% (0)	53
				<i>answered question</i>	<b>71</b>
				<i>skipped question</i>	<b>0</b>

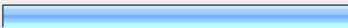
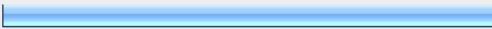


5. How would you rate the overall Community Genetics Forum?			
		Response Percent	Response Count
Excellent		55.7%	39
Good		41.4%	29
Fair		2.9%	2
Poor		0.0%	0
		<i>answered question</i>	<b>70</b>
		<i>skipped question</i>	<b>1</b>

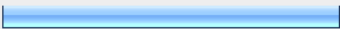
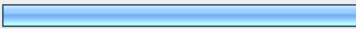
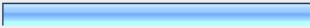

**6. What topics did you find most valuable? (selected comments from 47 responses)**



“I am not a scientist, but I found Dr. Collins to be an amazing speaker--he didn't lose my attention or talk over my head even once. But my personal favorite of the topics was Dena Davis's. The larger questions of identity and "truth" and definitions of community were incredibly interesting to me.” [The talks led by Francis Collins and Dena Davis were the two most popular of the Forum.]

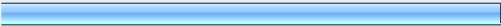


“As a clinician-scientist, I found the ethical issues very captivating and enlightening.”


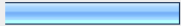
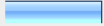



“Reaction panel and wrap up session. The information provided at this session was great. There was more information about what each person's job was about and the impact that we could have as science majors.”





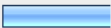
7. After Friday's forum, do you feel more informed about: (check all that apply)			
		Response Percent	Response Count
Genetics and Health		59.4%	41
<b>Ethical, Legal, and Social Issues</b>		<b>84.1%</b>	58
Genetic Research		66.7%	46
Other (please specify)		8.7%	6
		<i>answered question</i>	<b>69</b>
		<i>skipped question</i>	<b>2</b>



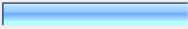

8. Which issues would you like to learn more about? (check all that apply)			
		Response Percent	Response Count
Genetics and Health		57.8%	37
<b>Ethical, Legal and Social Issues</b>		<b>60.9%</b>	39
Genetics Research		53.1%	34
Other (please specify)		10.9%	7
		<i>answered question</i>	<b>64</b>
		<i>skipped question</i>	<b>7</b>

9. Did you have an opportunity and did you feel encouraged to express your opinions and ideas?			
		Response Percent	Response Count
Yes		89.4%	59
No		10.6%	7
		<i>answered question</i>	<b>66</b>
		<i>skipped question</i>	<b>5</b>

10. Were your questions adequately answered?		
	Response Percent	Response Count
Yes 	84.9%	45
No 	5.7%	3
comments 	15.1%	8
<i>answered question</i>		53
<i>skipped question</i>		18

11. Please specify your current occupation:		
	Response Percent	Response Count
undergraduate student 	5.9%	4
graduate student 	29.4%	20
post/doc 	16.2%	11
Area University Faculty member 	27.9%	19
Area University Staff member 	7.4%	5
Area High School Teacher	0.0%	0
Other (please specify) 	13.2%	9
<i>answered question</i>		68
<i>skipped question</i>		3

12. Please specify the organization you are currently affiliated/enrolled with:			
		Response Percent	Response Count
UNC Chapel Hill		62.1%	41
Duke University		10.6%	7
NC Central University		0.0%	0
NC A&T University		7.6%	5
NC State		0.0%	0
NHGRI		1.5%	1
Other (please specify)		18.2%	12
		<b>answered question</b>	<b>66</b>
		<b>skipped question</b>	<b>5</b>

13. Please share your area of study/work:			
		Response Percent	Response Count
Research		73.7%	42
Clinical Practice		21.1%	12
Teaching		31.6%	18
Other		8.8%	5
		<b>answered question</b>	<b>57</b>
		<b>skipped question</b>	<b>14</b>

14. How do you describe yourself? (you may check more than one)			
		Response Percent	Response Count
American Indian or Alaska Native		4.8%	3
Asian		6.3%	4
Black or African American		14.3%	9
Native Hawaiian or other Pacific Islander		0.0%	0
<b>White</b>		<b>76.2%</b>	48
Hispanic/Latino		3.2%	2
Other (please specify)		1.6%	1
<i>answered question</i>			<b>63</b>
<i>skipped question</i>			<b>8</b>

15. If you are a student, how likely are you to enter the following fields? If you are not a student, please skip this question.							
	Extremely Likely	Possible	Unlikely	Impossible	Undecided	Rating Average	Response Count
Genetics/Healthcare	<b>50.0% (13)</b>	30.8% (8)	11.5% (3)	3.8% (1)	3.8% (1)	1.81	26
Ethical, Legal, and Social Issues	<b>46.2% (12)</b>	30.8% (8)	15.4% (4)	0.0% (0)	7.7% (2)	1.92	26
Genetic Research	<b>40.0% (10)</b>	36.0% (9)	8.0% (2)	12.0% (3)	4.0% (1)	2.04	25
<i>answered question</i>							<b>29</b>
<i>skipped question</i>							<b>42</b>

**16. Please share any additional comments about the Community Genetics Forum 2006.**

"I really enjoyed the opportunity to attend this forum especially on my home campus of UNC-Chapel Hill. The highlight of the day was the graduate student lunch with Francis Collins. I appreciated the opportunity to ask questions in a small group where a more intimate interaction was possible."

"Outstanding event. Very well organized. Informative. Thought provoking."

"I'm really happy to have participated. Thanks."

"Thank you for this opportunity."

"The sessions were excellent though and worth the time."

"I thought it was terrific, albeit a bit crowded!"

"It was a well designed program of events that was very relevant to a broad group of people. As a grad student I particularly found the career panel quite useful"

"The diversity and expertise of the speakers in the plenary sessions was outstanding, making for an extremely interesting variation in perspectives."

"I thought it was an EXCELLENT program and want to thank the organizers for an informative, inspiring day. Great job!!!!"

". . . the forum, especially on Saturday, was the best community interaction forum on the topic I have ever attended. Congratulations to the organizers for a job well done."

"Overall very productive event, particularly the opportunities to meet with and talk with members of NHGRI and learn about the challenges of the future, especially in the ELSI area"

"I hope the university will continue to support such conferences. it would be nice to support programs that would draw in a wider swath of the university. Since I have a background in both medicine and the humanities, I feel that there need to be conversations taking place. The different areas of study are not as mutually exclusive as they may seem."

"I really enjoyed the conference. The speakers were very approachable. I learned about many programs that I had not been previously exposed to. Overall, it was time well spent."

"This was a great conference. I was only able to attend the speakers but they were all amazing. I am not a student but a friend told me about the conference and I'm very interested in the topic, so I decided to attend. It definitely sparked my interest in learning more and possibly even pursuing genetics as an area of study. Thank you so much from bringing these great people to the area and opening it up to the public. "

"I thought it was great! I thoroughly enjoyed the social/ethic aspects as these are issues we (in the field of genetics) are not usually stimulated to think about."

"THIS WAS A WONDERFUL EXPERIENCE FOR ME AND I HOPE TO ATTEND MORE IN THE FUTURE. THE PANELIST WERE VERY INSPIRATIONAL"

"This was worth the time spent!"

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## Demographic Questions

### What year were you born? n= 146

1920-1929	1
1930-1939	11
1940-1949	5
1950-1959	26
1960-1969	11
1970-1979	20
1980-1989	50
1990-1999	19
n/a	3

### What is your gender? n=146

Female	98
Male	48

### What is your zip code? n=145

67 different zip codes reported.

31 people in 27510-27519 (Chapel Hill area)

49 people in 27701-27708, 27712-27713 (Durham area)

### How do you describe yourself: (check one or more; you may check more than one)

American Indian or Alaska Native	4
Asian	23
Black or African American	10
Native Hawaiian or Other Pacific Islander	0
White	110
Hispanic/Latino	6
Other (please specify)	1 (Southeast Asian)
n/a	1

### Last week were you (circle all that apply) . . .

Working full time	49
Working part-time	19
Student	
High school	33
Undergraduate	27
Graduate	10
Not specified	12
Retired	14
Unemployed	9

### If employed, what is your primary occupation?

70 individuals listed an occupation. Many respondents were in the teaching, research, or medical fields, however, they also included such occupations as organic gardener, kitchen and bath designer, social worker, and engineer.

### If you are a student, what is your school, college or university?

83 students listed their affiliations. Attendees represented 18 different institutions: 11 colleges and universities, which included Duke University (25), UNC-Pembroke (10), UNC-Chapel Hill (6), and 5 secondary schools, which included NC School of Science and Math (25), Carolina Friends School (5), and Cary Academy (3).

## Evaluation/ Feedback Responses

**1. What is your overall evaluation of this event:** n=41

Excellent	28
Good	12
Fair	1
Poor	0

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

Topics included: Ancestry and DNA, Designer Babies and Ethics, Dr. Francis Collins' lecture on the future of genetics and the social implications of genetics, and Genetics, Heart Disease and Diabetes.

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

Genetics and health	23
Ethical, legal, social issues	36
Genetic research	21
Other: (please describe)	5

Other topics noted: Haplotypes & DNA extraction, genetic research & availability in medical applications, attitudes of people toward controversies about genetics, arts in combination with science, nursing implications.

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

Genetics and health	20
Ethical, legal, social issues	17
Genetic research	22
N/A	4
Other: (please describe)	5

Other topics noted: Evolutionary/population/migration genetics, Genetic & health from a nursing standpoint with research, future genetic technologies for those w/o health insurance, pharmacogenomics, family history.

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

Yes	35
No	5
N/A	1

Several respondents commented that there was not enough time for questions.

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

Yes	33
No	3
N/A	5

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

Genetics/healthcare	18
Ethical, legal, social issues	10
Genetic research	11
Other	5
Not a student	6
N/A	12

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**8. Which breakout sessions did you attend: (check those that apply)**

Ancestry Testing, Understanding our Heritage through DNA	9
DNA & Health: The Role of Biomedical Research	8
Genetic Enhancement & Designer Babies: Can we?, should we?	11
Privacy & DNA: Who should and can know your private DNA information?	2
Genetics, Behavior & Ethics: What do genes have to do with your personality?	15
Genetics, Heart Disease, Diabetes, and Cancer	14
The Liz Lerman Dance Exchange Workshop	2
Forensics & DNA	6
DNA Extraction! for Kids and Adults alike	1
N/A	2

**9. How did you learn about today's forum?**

Flyers posted at the Durham Public Library, from instructors/ schools/ departments, Parr Center website, Durham Genealogy Society, email from NC Museum of Life and Science.

**Additional comments:**

"I was very impressed with panel conducting Ancestry Testing."

"This overall was a wonderful weekend event & I look forward to future research study and forums."

"I enjoyed Dr. Collins lecture on DNA & explanation of advances with the Genome Project on Friday."

"I really enjoyed this meeting and learnt a great deal. It has definitely cemented my interest in genetics."

"I really liked the speakers and that there was more than one of them speaking-they worked off of each other. I wish we had more time in the concurrent sessions."

"Overall I really enjoyed the conference and it has motivated me to be more genetically inclined. I truly feel motivated to be an advocate & liaison for . . ."

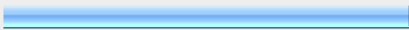
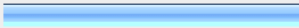
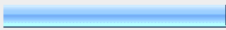
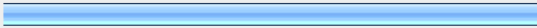

"Thank you for having this program. It was very interesting and informative. Please have other similar type topics for the area."


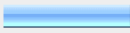



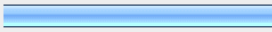

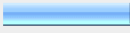

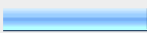
"The group from NHGRI was outstanding. Enthusiastic, great teachers, approachable. Their passion is evident."

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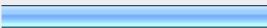
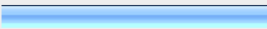

Addendum: Survey Results from NCSSM Participants of the CGF

Students were invited to fill out an on-line evaluation survey using SurveyMonkey.com. The following tables were created using the reporting tools on SurveyMonkey.com.

1. Which Community Genetics Forum events did you attend? (please choose all that apply)		
	Response Percent	Response Count
Breakfast with Dr. Collins 	68.8%	22
Plenary Lectures (Dr. Collins, Dr. Harry & Dr. Davis) 	50.0%	16
Community Town Hall Panel 	37.5%	12
<b>Breakout Sessions</b> 	<b>90.6%</b>	<b>29</b>
Wrap-up Discussion 	34.4%	11
Other (please specify)	0.0%	0
	<i>answered question</i>	<b>32</b>
	<i>skipped question</i>	<b>1</b>

2. If you attended breakout sessions, which ones did you attend?		
	Response Percent	Response Count
Did not attend a breakout session 	9.1%	3
Ancestry Testing: Understanding our Heritage Through DNA 	21.2%	7
DNA & Health: The Role of Biomedical Research 	9.1%	3
Genetic Enhancement & Designer Babies: Can we? Should we? 	15.2%	5
Privacy & DNA: Who Can and Should Know your Private DNA Information? 	9.1%	3
<b>Genetics, Behavior, &amp; Ethics: What do genes have to do with your personality?</b> 	45.5%	15
Genetics, Heart Disease, Diabetes, and Cancer 	3.0%	1
The Liz Lerman Dance Exchange Workshop	0.0%	0
Forensics & DNA 	21.2%	7
DNA Extraction! 	3.0%	1
What's New and Exciting in Genomics Research?!?! 	24.2%	8
	<b>answered question</b>	<b>33</b>
	<b>skipped question</b>	<b>0</b>

3. Please rate the following activities. If you did not attend a particular event, please choose N/A.						
	Excellent	Good	Fair	Poor		Response Count
Breakfast with Dr. Collins	53.1% (17)	12.5% (4)	0.0% (0)	0.0% (0)		32
Plenary Lectures	3.4% (1)	24.1% (7)	24.1% (7)	0.0% (0)		29
Community Town Hall Panel	6.9% (2)	13.8% (4)	13.8% (4)	3.4% (1)		29
Breakout Sessions	40.6% (13)	40.6% (13)	9.4% (3)	0.0% (0)		32
Wrap-up Discussion	26.7% (8)	10.0% (3)	0.0% (0)	0.0% (0)		30
	<i>answered question</i>					32
	<i>skipped question</i>					1

4. How would you rate the overall Community Genetics Forum?			
		Response Percent	Response Count
Excellent		45.2%	14
Good		45.2%	14
Fair		9.7%	3
Poor		0.0%	0
	<i>answered question</i>		31
	<i>skipped question</i>		2

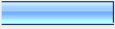
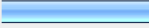
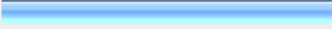
**5. What topics did you find most valuable?**

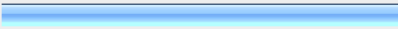
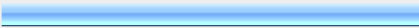


The "Breakfast with Dr. Collins" was very popular with the respondents. Students also appreciated the discussions on What's New and Exciting in Genetics and ethical issues.

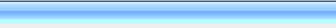
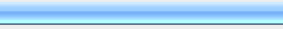
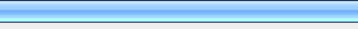

"I enjoyed the breakfast with Dr. Collins; I thought it was amazing."

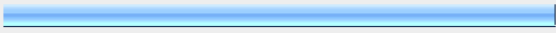

"I found the topics that Dr. Collins covered to be the most valuable and extremely interesting."

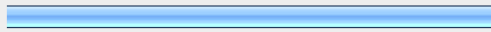

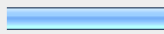
"I really enjoyed the topic on Ancestry. The information that was given altered my view about the field of genetics altogether."

6. Were you familiar with Dr. Collins and his work before the Forum?		
	Response Percent	Response Count
Yes 	18.8%	6
No 	25.0%	8
A little bit 	56.3%	18
<i>answered question</i>		<b>32</b>
<i>skipped question</i>		<b>1</b>

7. After the forum on Saturday, do you feel more informed about: (check all that apply)		
	Response Percent	Response Count
Genetics and Health 	67.7%	21
Ethical, Legal, and Social Issues 	71.0%	22
<b>Genetic Research</b> 	87.1%	27
Other (please specify) 	3.2%	1
<i>answered question</i>		<b>31</b>
<i>skipped question</i>		<b>2</b>

8. Which issues would you like to learn more about? (check all that apply)		
	Response Percent	Response Count
Genetics and Health 	58.1%	18
Ethical, Legal and Social Issues 	48.4%	15
<b>Genetics Research</b> 	61.3%	19
Other (please specify) 	6.5%	2
<i>answered question</i>		<b>31</b>
<i>skipped question</i>		<b>2</b>

9. Did you have an opportunity and did you feel encouraged to express your opinions and ideas?		
	Response Percent	Response Count
Yes 	93.5%	29
No 	6.5%	2
<i>answered question</i>		31
<i>skipped question</i>		2




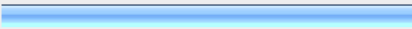
10. Were your questions adequately answered?		
	Response Percent	Response Count
Yes 	83.3%	25
No 	13.3%	4
comments 	26.7%	8
<i>answered question</i>		30
<i>skipped question</i>		3

**12. Please share your career interests/goals.**

17 of 27 responses indicated an interest in a career involving a branch of medical science (e.g. pediatrics, genetics, biomedical engineering, neuroscience). Other career interests mentioned included: teaching, environmental law, journalism, computer science, and diplomacy.





13. How do you describe yourself? (you may check more than one)		
	Response Percent	Response Count
American Indian or Alaska Native	0.0%	0
Asian 	23.3%	7
Black or African American 	6.7%	2
Native Hawaiian or other Pacific Islander 	3.3%	1
White 	70.0%	21
Hispanic/Latino	0.0%	0
Other (please specify)	0.0%	0
<i>answered question</i>		30
<i>skipped question</i>		3

14. How likely are you to enter the following fields? If you are not a student, please skip this question.							
	Extremely Likely	Possible	Unlikely	Impossible	Undecided	Rating Average	Response Count
Genetics/Healthcare	33.3% (10)	26.7% (8)	30.0% (9)	6.7% (2)	3.3% (1)	2.20	30
Ethical, Legal, and Social Issues	6.5% (2)	38.7% (12)	45.2% (14)	9.7% (3)	0.0% (0)	2.58	31
Genetic Research	16.7% (5)	46.7% (14)	30.0% (9)	6.7% (2)	0.0% (0)	2.27	30
<i>answered question</i>							31
<i>skipped question</i>							2

**15. Please share any additional comments about the Community Genetics Forum 2006.**

"The Community Genetics Forum was very informative and exciting. It was great to hear about cutting edge advances being made in the field, as well as all of the social and ethical issues that follow them.

"I greatly enjoyed everything that went on during the Genetic Town Meeting 2006. It was a shame that we could only attend two break-out sessions, for I would have loved to take part in the ones that I had missed."

"I think that the genetics town Meeting was pretty well planned and it was enjoyable having the entire Durham community be involved."

"It was a wonderful opportunity to learn more about Genomics Research and its impact on our world today."

"We should do it again next year. It was great."

"I thought that this was a great experience and that it was very well done. I especially enjoyed all of the breakout sessions that were held! They really fostered individual thinking and questioning of genetics as it is today. I will definitely come to anything similar to this in the future."

