

Oct 2006

# Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Graduate Program

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## Program News

We are pleased to welcome the class of 2009:

- Melanie Baxter from Columbia, Missouri
- Mindy Simonson from Longmont, Colorado
- Megan Truitt from Salisbury, Maryland
- Gillian Hooker from New Haven, Connecticut
- Julie Cohen from Baltimore, Maryland

We were extremely fortunate to have recently add the following faculty to the Executive Committee:

- Lori Hamby Erby, MS, JHU
- Alan Guttmacher, MD, PhD, NHGRI
- Kimberly Kaphingst, PhD, NHGRI
- Donna Krasnewich, MD, NHGRI
- Howard Levy, MD, PhD, JHU
- Holly Peay, MS, NHGRI

Barb Biesecker won two special awards this year, the NHGRI Mentoring Award and the NIH Director's Mentoring Award! Congratulations!



In March of 2006, we were pleased to once again host Seymour Kessler at the NIH. Seymour conducted a weekend-long supervision with the students, listening to audio-tapes of their work and focusing on building their counseling skills. He also conducted an in-service for area clinical supervisors that, according to their evaluations, they found most useful. We hope to invite Seymour back this spring. At 76 years of age, he is as insightful as ever!

News of our recent graduates:

- Alissa Bovee worked for several months at INOVA in VA, and recently relocated to Ithaca, NY with her husband, Steve. She has begun a part-time prenatal job in Binghamton at the Ferre Institute.
- Kate Reed works at NCHPEG three days per week as a project director, and two days per week at the Univ. of MD in their pediatric and cancer genetics clinic.
- Suzanna Schott accepted a genetic counseling position at the Univ. of NM at Albuquerque where she and her husband, Taylor, are exploring the Southeast. Suzanna has a busy clinical position with challenging multi-cultural counseling issues.
- Meredith Weaver has also been working in the department of pediatrics at the Univ. of MD and recently began the doctoral program in Health, Behavior, and Society at the JHU Bloomberg School of Public Health.

## DNA Day

DNA day was April 25th, and many of our students and faculty participated in the NHGRI DNA day activities. National DNA Day is a unique day where students, teachers and the public learn more about genetics and genomics. It was created to commemorate the completion of the Human Genome Project in April 2003.

Second-year student Jackie Douyard described her DNA-day experience:

"I spoke to three classes of tenth graders at Northwestern High School in Hyattsville, MD. We discussed the Human Genome Project and how it might have an impact on them in the future. We talked about their family history and health as well as various career options they can pursue. I also introduced them to the profession of genetic counseling and presented hypothetical cases for them to work through as if they were the genetic counselor. It was very rewarding to work with teachers and students who were interested in the field and eager to participate in the discussions."

Our students traveled across the country to visit traditionally underserved schools in MA, NH, CT, and MD. For more information on DNA day resources and activities, see <http://www.genome.gov/10506367>

## Thesis Studies

Our third-year students are busy collecting and analyzing data for their studies:

Through a study entitled "Genetic Counselors' Experiences of Moral Value Conflicts with Clients," Rachel Jacobson seeks to gain insight into the nature, sources, and consequences of moral value conflicts among genetic counselors through the use of semi-structured, in-depth interviews with approximately 30 genetic counselors. The discussion centers on a personal experience of moral value conflict that the counselor has had with a client. An understanding of value conflicts may allow for future interventions to minimize the negative effects of these events.

Jamie Dokson's study, entitled "Experiences of Genetics Patients with Visible Abnormalities who Facilitate Teaching in Genetics Clinics," aims to describe the experience of genetics patients. Participants are asked about their experiences when visiting the genetics clinic, the circumstances under which they have been approached to par-

ticipate in teaching, their perspective on specific teaching behaviors used in genetic consultations, the benefits and downsides of being involved in teaching others, and the circumstances under which they feel comfortable being approached by genetics providers to help teach others about their condition. Information from this study may be used to enhance educational experiences in genetics clinics.

Colleen Brown's thesis study is entitled, "Invasive Prenatal Testing Decisions in Pregnancy after Infertility." This study explores the decision-making experiences of women who are pregnant after a period of infertility and have decided whether or not to undergo invasive prenatal testing. Colleen is investigating how this unique context affects women's decision-making experiences. Her survey measures infertility-related distress, subjective norms, and test decision and decisional conflict as outcome variables. Her findings will have important implications for prenatal genetic counseling of previously infertile women.

Matt Thomas's study, entitled "Exploring the general public's beliefs, feelings, and behaviors towards the healthy siblings of individuals with mental illness," examines how attributing mental illness to a genetic cause affects stigma towards affected individuals and unaffected siblings. The two main goals are, 1) to explore the relationships between the general public's cognition, affect and behavior towards individuals with mental illness, and the general public's behaviors towards siblings of those with mental illness and 2) to explore how the type of relationship between the sibling and a person with mental illness (i.e. biological sib or adopted sib) influences the general public's stigmatization of the sibling. Results from this study may be used to design genetic mental health services interventions for the public.



## Medical Director Bob Nussbaum Departs

Bob Nussbaum served as Medical Director from the inception of the Program, ten years ago. While this is not precisely true (others served terms as medical director), it was indeed Bob who was the medical backbone and soul of the Program. Behind the scenes, Bob nurtured the students, the faculty, the curriculum, and me, as Director. He was a mentor in the truest form, not looking to gain anything for himself, but giving of his insight, reason and experience to help shape and enhance the Program. What a great gift he was these ten years! We wish him all the best at UCSF!!

~ Barb Biesecker

## Reminisces from our third-year students

Each week Bob Nussbaum gave up 2 hours of his highly-demanded time to sit down with just 4 or 5 students (often over cookies) and discuss everything from recombination in meiosis to gonadal maldevelopment. When someone did not understand a concept that was mentioned in the textbook (that HE wrote), he would explain it a completely different way. Sometimes his alternate explanations involved contorting his body in awkward positions in order to demonstrate, for example, how an ultrasound may misinterpret the gender of a fetus (see Figure 1). If a student did not “get it”, Bob would take additional time out of class to meet with that student one on one. We feel for the future students who won’t even know what they missed. What does San Francisco have that we don’t have?... Well, I guess they have Bob. Our tremendous loss.

## Musings from our second-year students

We feel incredibly honored to have been the last of many lucky classes to have Bob as our teacher. It’s funny to say that, considering how intimidated we were on that first night of class when we realized there was no possible way to not prepare, sit in the back of class, and sleep. We soon began bringing our abundantly-highlighted books to class as an offering of some proof that, yes, we owned the book, and yes, we read it faithfully—since our performance in class might have led Bob to believe otherwise. And when it was over, we missed Bob right away. For what he taught us was more than just the facts. We learned the joys of pursuing knowledge with friends, and that the best kind of learning lasts you a lifetime. We know we have been prepared well for whatever lies ahead, and we won’t forget: it’s GENETIC counseling!

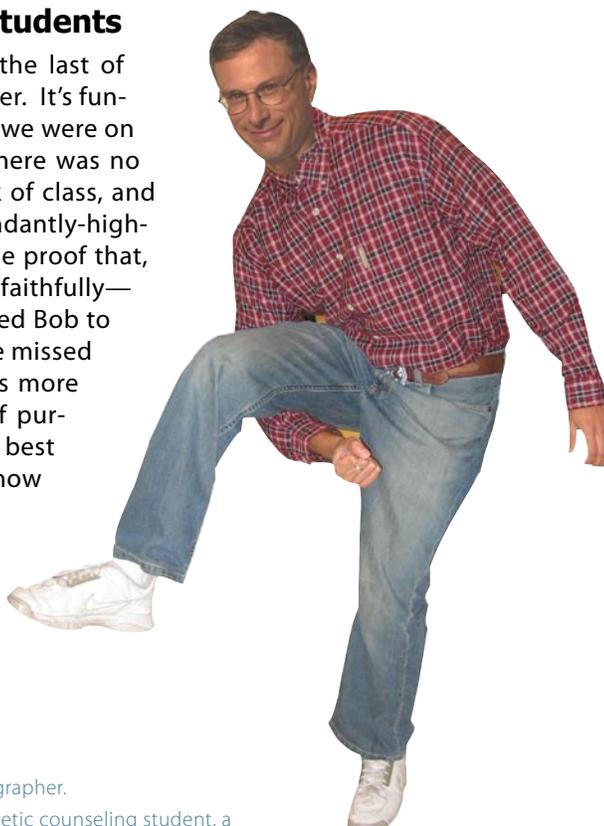


Figure 1. How an in-utero female might deceive an ultrasonographer.

(This photo appears courtesy of Bob’s old NIH headshot, a genetic counseling student, a digital camera, and Photoshop™.)

## Hurricane Katrina Volunteer Efforts

By Colleen Brown and Matt Thomas, third-year students



When hurricane Katrina hit the gulf coast on August 29th, we were scrambling to do some of the background research for our theses that we had managed to neglect over the summer. But as we sat at our computers pouring over lit searches we were quickly distracted by the news from Louisiana. We discussed with our classmates how incredibly tragic the event was and how unnecessary and avoidable the suffering appeared. Suddenly our looming thesis deadlines didn't seem so important.

We made donations to the relief efforts, wishing we could do something more tangible to help. We lamented that our nascent genetic counseling skills just didn't seem to equip us to help in an emergency like this. If only we'd chosen to become paramedics, animal rescuers, or another occupation trained to respond to natural disasters. Little did we know how wrong we were!

A few months later, when Barb informed us that there was indeed a specific way that our unique set of skills could help the victims of Katrina, we jumped at the chance to contribute. In mid-January, a few weeks before graduation, six students (Kate Reed, Meredith Weaver, Suzanna Schott, Alissa Bovee, Matt Thomas, and Colleen Brown) and three faculty members (Barb Biesecker, Trish Magyar, Holly Peay) headed down to Baton Rouge, Louisiana to help with the effort to identify victims through DNA testing. Moved by our experiences in January, Barb and four students (Rachel Jacobson, Jamie Dokson, Matt Thomas, and Colleen Brown) made a second trip in March.

The work proved to be a perfect match for the skills in a genetic counselor's toolbox: we managed cases, took family histories, explained genetic testing, provided grief counseling, and advocated for families. What we had not anticipated was how much detective work we would be doing. We spent much of our time digging through internet searches and public records, trying to put together scattered puzzle pieces so that we'd be able to locate a family member to give a DNA sample, find a missing person, or reunite a family. Each time our gumshoeing identified a missing person as alive we'd get to ring a bell. This gesture helped to bolster motivation and hope in the call center we were working in.

None of us are hoping for another disaster like Katrina or 9/11 that requires DNA-based identification of victims. But we now know that when such a tragedy strikes, we can indeed help in a very specific and meaningful way.

### A New Public Health Genomics Course: Genetic Counselors as a link between genomics and public health?

At the end of the spring semester, we piloted a new intensive two-week course at the NIH called, "Applications of Genomics to Public Health Challenges." Drs. Colleen McBride and Christopher Wade led the course that focused on how rapidly accumulating genomic research may be adopted by the field of public health, and what role genetic counselors might play in facilitating this connection.

The first week consisted of lectures by experts in fields related to genomics and public health. Discussions addressed several questions: How do you stratify populations to effectively engage in public health campaigns? What are the most effective ways of communicating complex genetic information to the public? When is it appropriate to carry out population screening with genetic tests? How do you gauge the cost effectiveness of an intervention? How might genetic services be integrated into health services delivery systems? What issues face a primary prevention intervention? How can one engage a community for public health interventions? Workshops followed that asked the students to apply the materials to practical scenarios.

The second week focused on independent research projects. The students worked in groups to design an intervention for one of three hypothetical scenarios. The first examined the public health implications of a polymorphism that was associated with a negative inflammatory reaction to RU486. Another group designed a smoking cessation intervention for a genetic variant that greatly increased risk for cardiovascular disease and lung cancer in the presence of tobacco smoke. The third group discussed avian flu vaccine distribution during an outbreak in the context of a variant that increased susceptibility to infection. Each group then presented their intervention to the class in the form of a proposal for funding to the CDC.

Although it remains unclear to what extent genomics will be integrated into public health, we believe that genetic counselors should play a significant role in the transition. Genetic counselors' training and experience will be invaluable for developing effective public health strategies. Overall, the course succeeded in meeting its goal of facilitating discussions about public health genomics, and we plan to offer it biannually.

### Welcome to New Medical Director



**SPECIAL WELCOME TO OUR OUTSTANDING NEW MEDICAL DIRECTOR: ALAN GUTTMACHER, MD, DEPUTY DIRECTOR, NHGRI!!** We are so fortunate to have such a prominent new medical director for our Program, and we are grateful to Alan for agreeing to take on this role in addition to his extensive list of Institute responsibilities. Alan is well known to the Program as he has lectured and advised the Director and faculty in several instances. His warmth, thoughtful guidance, and expertise are greatly appreciated by faculty and students alike.

### Thanks to the Ongoing Efforts of the Program's Executive Committee:

Barbara Bowles Biesecker (Program Director), Lori Hamby Erby, Alan Guttmacher (Medical Director), Ada Hamosh, Kimberly Kapingst, Donna Krasnewich, Howard Levy, Trish Magyari, Colleen McBride, Holly Peay (Associate Director), Rajiv Rimal, Debra Roter (Academic Director), Joan Scott, and Larry Wissow.