# Tackling Tough Questions

A talented septet of NIEHS interns from undergraduate and graduate programs in the U.S. and abroad came together this summer to take a close, hard look at the challenging and sometimes thorny ethical issues facing today's researchers in environmental health. Selected from over 55 applicants nationwide, the seven students participating in the institute's Program in Environmental Health Policy and Ethics (PEHPE) spent the summer examining policy issues and conducting research with guidance from senior institute scientists and under the mentorship of program director Richard Sharp. This is the first time the NIEHS has offered a program on this scale, explains Sharp, who says he doesn't know of another program that gives students the opportunity to examine ethical and policy issues in environmental health research. He adds that there were several international applicants this year and that he wants the program to involve international participants because "environmental policies are very different in different parts of the world."

Before delving into their projects—which examined issues in environmental regulation and policy, the impact of new technologies on risk assessment and risk management, toxicogenomics, environmental justice, and protection of human subjects in research—the seven spent a week in workshops featuring experts from throughout the institute. Throughout the summer, group members shared their discoveries by leading weekly conferences on subjects ranging from concepts of race and ethnicity in biomedical research, to collecting biological materials for research, to understanding social, regulatory, and legal issues in toxicogenomics.

### Many Angles to Policy and Ethics

Cynthia Wright, a fourth-year sociology doctoral student at North Carolina State University, says the program has broadened her perspective on the ethical implications of scientific research. She collaborated with Nicole Collins—a senior at the University of Wisconsin at Madison pursuing a degree in biomedical ethics—on several projects. One used focus groups to assess the attitudes and motivations of patients with alpha-1 antitrypsin deficiency—a genetic lung disease—who participated in patient support groups. "We wanted to see what they expected from their involvement [in support groups] and how support group involvement affects attitudes regarding treatment options and other clinical decisions," Wright explains. "In pure science, social [factors] get omitted, but here [in the PEHPE] everything is taken into account, including psychology, work environment, class, etc."

Collins agrees that the human dimension is important, fascinating, and virtually impossible for a student to grasp in the classroom setting. Class offers but a textbook glimpse at ethics issues through hypothetical case studies, she says. In the very real setting of the alpha-1 focus groups, she learned that patients were very concerned about insurance discrimination and a possible conflict of interest between pharmaceutical companies and the Alpha-1 Association, which advocates for patients with the disease. "There's nothing like hearing from the patients," she says. "With the focus groups, I got to listen to their feelings, thoughts, and emotions. You remember they are humans and [learn to] hold that in the highest regard."

Samarys Seguinot Medina learned about the PEHPE from her dean at Puerto Rico's Metropolitan University, where she is working toward her master's degree in environmental risk management and assessment. She spent the summer studying ethical issues surrounding exposure to pesticides in Hispanic farm workers in North Carolina. Besides the problem of occupational exposure itself, the medical and research communities are challenged by farmworkers' personal perceptions and cultural beliefs about pesticide exposure, as well as language barriers. "The farmworkers—mostly Mexicans, along with some Puerto Ricans and Central Americans—don't believe that exposure to [toxicants in pesticides] could cause cancer," Medina says. "They also don't trust health care providers."

In an extensive literature review, Medina combed scientific, legal, news, and social sciences databases for all articles on pesticides and Hispanic farmworkers in North Carolina. After reading and summarizing these articles, she analyzed past cases in U.S. agriculture that involved Hispanics and the risk of occupational exposure to pesticides. Since then, she has focused on risk communication—getting the message from the agency to the farmers and the farmworkers—by unveiling communication barriers and educating farmers and workers about exposure consequences. The keys to successful communication, Medina says, are twofold: removal of the language barrier and more education for farmers—not only about pesticide exposure, but also about cultural issues.

Ryan Ashley, a junior health policy and administration major at the University of North Carolina at Chapel Hill, undertook a science-driven project with policy implications under the direction of Jean Harry, head of the NIEHS Neurotoxicology Group. He looked at regulatory applications of certain National Toxicology Program (NTP) bioassays and determined if and how NTP data are being used by the U.S. Environmental Protection Agency in setting reference doses for its list of registered chemicals.

"One of my main goals was to find out if there are other sensitive end points that would signal that a chemical is a developmental toxicant [in addition to those already published], and then tag them onto existing studies, and thus save the government a lot of money each year," Ashley explains. To search

**2001 PEHPE participants.** Back row, left to right: Matthew Davis, Ryan Ashley, Richard Sharp, Michael Yudell, Paul Zigas; front row, left to right: Samarys Sequinot, Cynthia Wright, Nicole Collins.

Steve McCaw/Image Associates, Inc.

for such end points, he reviewed an existing NTP paper on developmental toxicology published in the April 1993 issue of *EHP,* collected data from newer NTP studies, and put his findings into tabular form.

When the tabulated data are published Ashley hopes to be named a contributor to the paper—heady stuff indeed for an undergraduate. Ashley, who wants to become a health care administrator, says his experiences as an intern this summer have changed his perspective. "It's given me a better sense of how science affects health care decisions and vice versa," he says.

### Asking the Right Questions

Sharp says the interns typically come in with big ideas and learn to scale them back. "They learn to ask the smaller questions that lead to an understanding of the big picture," he explains. Besides learning how to ask questions, they learn to expand on the work of others in a novel way. "A big part of becoming a successful researcher in any field is learning what questions to ask and knowing which research developments are important," he says.

Asking questions comes naturally to intern Michael Yudell, a doctoral student in Columbia University's program in the history and ethics of public health and medicine. Yudell is coauthoring a paper on genome policy with NIEHS deputy director Samuel Wilson. As an environmental historian, Yudell is interested in looking at prior models of national action in the science, technology, and environmental arenas, for example regulations in the nuclear power industry or policy regarding recombinant DNA technology. By looking at such models, Yudell hopes to learn whether regulatory issues could have been handled differently or better. Or, Yudell philosophizes, "Do we have to have [an environmental health] disaster first? We've been reactive in the past. Now we need to be proactive."

Yudell says his participation in the PEHPE has given him vital exposure to a group of professionals with a different focus. "Before, I worked mainly with historians, and here it's been mainly scientists," he explains. "Working with [Sharp] and Dr. Wilson has enriched my dissertation."

Another intern, Mathew Davis—a Duke University senior who plans to attend medical school and simultaneously pursue a Ph.D. in medical ethics—collaborated with Sharp on a content analysis of eight policies designed to protect community interests during the collection of biological samples for research. Together they produced a set of guidelines that specifically addressed issues of community harm, interest, and respect for American Indian and Native Alaskan communities, including community consultation, sample collection, use and storage of biological materials, prioritizing research uses, and postresearch obligations of researchers and research sponsors.

Paul Zigas—a third-year law student at the University of North Carolina at Chapel Hill who is also working toward his master's degree in toxicology at North Carolina State University—spent the better part of his summer conducting a mammoth literature search. Using news databases such as Web of Science, PubMed, and LexisNexis, Zigas corralled all the literature citations on the topic of toxicogenomics into one EndNote library. From these he selected 70 articles, annotated them, and provided them as background material for the National Center for Toxicogenomics Working Group on Ethical, Legal, and Social Implications of Toxicogenomic Research, whose investigation into ethics will inform policy for that new center.

### Unlocking a Mystery

Besides gaining valuable research experience, the interns receive intensive training. "We book them solid," says Sharp of the opening series of workshops, which covered not only issues in environmental policy and ethics but also topics such as searching online databases, using software packages, and doing presentations. "They do a presentation here and when they go back [to their universities], as well as prepare posters to be presented at national conferences," Sharp says.

The program also elucidates the scientific process. "The NIH has a certain mystique," Sharp says. "It issues a mandate, but people wonder where it comes from and what motivates the policy." The program provides a two-way benefit: "Hearing from NIEHS researchers and administrators helps take the mystery out of the process and helps make the system more accessible to the interns," Sharp explains. "[The program] also encourages the researchers to rethink their perceptions of policy issues and to be more reflective about their impact socially."

Sharp say he benefits from the interns' endless supply of enthusiasm. "You invest a lot of time developing meaningful research projects that students can manage and complete in such a short time, but then you get rewarded by seeing the students develop and grow," he says. "Most people engaged in research don't get a chance to [teach] and work with very bright students. I find it very rewarding." **–Jennifer Medlin**

## New Scientific Director for NIEHS

Lutz Birnbaumer has been named the new scientific director of the NIEHS, where he will direct the institute's $63 million intramural research program. "Dr. Birnbaumer's research and leadership will further enhance the outstanding programs developed under the leadership of [former scientific director] Dr. Carl Barrett," said NIEHS director Kenneth Olden in announcing Birnbaumer's appointment. "Dr. Birnbaumer has the right combination of vision, intellect, and administrative skills needed to move NIEHS to the head of the class."

Mariel Birnbaumer

A native of Austria, Birnbaumer earned his master's degree and doctorate in biochemistry at the University of Buenos Aires. He worked as a postdoctoral fellow under former NIEHS scientific director Martin Rodbell at the National Institute of Arthritis and Metabolic Diseases. Birnbaumer comes to the institute from the University of California at Los Angeles, where he was a professor in and chair of the department of molecular, cell, and developmental biology. He also served as a professor of anesthesiology and biological chemistry there, and was a full member of the school's Institute of Molecular Biology, Brain Research Institute, and Jonsson Comprehensive Cancer Center.

Prior to his appointment, Birnbaumer was a member of the NIEHS Board of Scientific Counselors, an external panel that reviews the work of the Division of Intramural Research. He has also been involved with the Salk Institute, the American Heart Association, and the Pew Charitable Trusts. He has taught international graduate courses in cell biology around the world and has been a visiting professor at nearly 60 teaching institutions.

"Under Lutz's guidance, I am confident that our commitment and pursuit of excellence will continue," said Olden. "He is just the right person to restock the institute with the kind of scientific talent needed to be competitive in the present scientific climate." –Susan M. Booker