

Mission: Educational

The mission of the NIEHS is to reduce the burden of human illness and dysfunction from environmental causes by understanding the interrelationship between environmental factors, individual susceptibility, and age. The institute pursues this mission primarily through biomedical research, but in order for these findings to impact human health, they must be relayed to the public—and that includes students, from kindergarteners who are just beginning to learn about air, water, and plants, to college students preparing for careers as scientists.

"Most American schoolkids understand the need to 'save the environment,' [but] most do not understand the interaction between environment and human health," says Marian Johnson-Thompson, director of education and biomedical research development at the NIEHS. "Given how much that interaction can affect them personally and the importance of an informed citizenry in supporting wise government policies, we need to be involved in environmental health science education."

Education is a component of many activities taking place throughout the NIEHS. Indeed, says Liam O'Fallon, program analyst for the NIEHS science education and outreach grant programs, "Science education is really a part of all our jobs here at the institute."

Curriculum for Change

O'Fallon chairs the newly formed NIEHS Science Education Committee, which brings together the diverse educational activities throughout the institute and focuses on how these can better address student and teacher needs at the local and national level. One of the outcomes of this collaborative effort has been the development of a comprehensive NIEHS environmental health science education website (<http://www.niehs.nih.gov/science-education/>). The website provides access to an enormous amount of information on environmental health science, including homework resources and online activities for students, lesson resources and

classroom activities for teachers, and presentation materials for scientists. The site also lists opportunities for professional development, summer research and job opportunities, and tours and visits of the campus. [For more information on the site, see "NIEHS Environmental Health Science Education, p. A805 this issue.]

in natural science or engineering. Through its K–12 educational programs, the NIEHS seeks to help reverse both these trends.

Starting in 1994, the institute provided grants to universities to develop K–12 level instructional materials on such topics as cell biology, toxicology, risk assessment, scientific process and methodology, and indoor and outdoor air pollution. These instructional materials were meant to be incorporated into existing curricula.

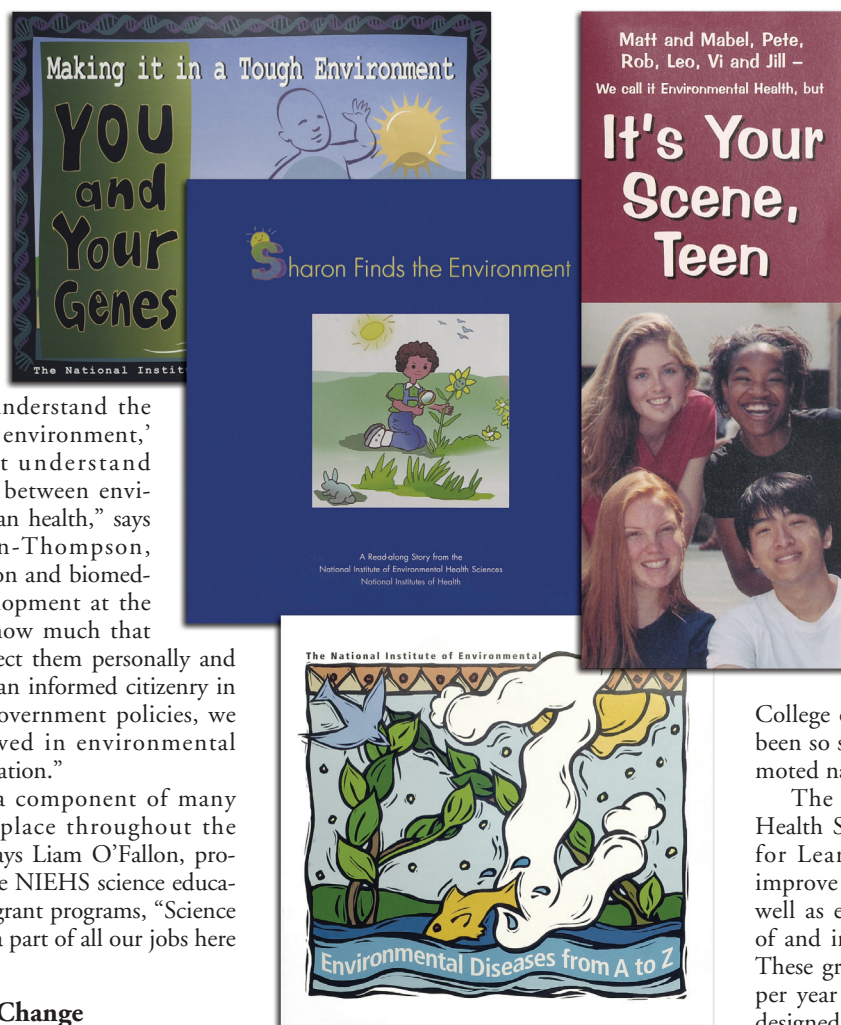
The institute followed these instructional materials development grants with grants aimed at teacher enhancement and development. Grantees provided teachers with materials and curricula pertaining to environmental health science, funding to attend workshops, and opportunities to interact with environmental health scientists in the field. Under this initiative, grantees trained more than 7,500 classroom teachers to incorporate environmental health science into their classrooms. Some curricula, such as the My Health My World series produced by the Baylor

College of Medicine for grades 2–4, have been so successful that they are being promoted nationally.

The latest initiative, Environmental Health Sciences as an Integrative Context for Learning (EHSIC), is intended to improve overall academic performance as well as enhance students' comprehension of and interest in environmental sciences. These grants, which offer up to \$250,000 per year for seven years, support projects designed to integrate environmental health science into a variety of school curricula. The nine recipients, several of whom received earlier grants for instructional materials and teacher development, are now entering the fifth year of their projects and are showing impressive results.

Reaching the Grassroots

The University of Rochester Medical Center has used its EHSIC grant to develop multidisciplinary curriculum units for grades 5–12. All units have a problem-based learning component, include hands-on activities, and integrate science with other subjects such as health, English, and social



Class-y materials. The NIEHS produces a number of free environmental health educational materials for teachers to use in the classroom.

The bulk of the institute's education efforts are aimed at boosting environmental health science education in kindergarten through twelfth grade (K–12). Various studies, including the High School and Beyond survey of the National Center for Education Statistics, have cited a steady decline in both the scientific literacy of American students and the number of students interested in pursuing careers

studies. Kim LaCelle, formerly a science teacher at Marion High School in western New York and now a science educator at the University of Rochester Life Science Learning Center, describes activities that the students in the rural community of Marion found particularly relevant.

"We addressed local environmental health issues, such as how farmers handle agricultural waste," LaCelle says. "With the NIEHS grant, we bought equipment to test wells for fecal coliforms. Another group mapped out the waterways that collected runoff from the fields and tested those for pesticides. The kids really enjoyed designing their own experiments. They developed a lot of confidence in their ability to do science."

Cathy Hoppe, a special education teacher working with schools in west Rochester, found the activities well suited to her learning-disabled students. "The problem-based learning unit engaged my kids right from the start," Hoppe says. "We presented them with a story about a child who discovers a polluted creek. They had to find out what kind of pollution it was. They used the Internet and went on field trips. It's wonderful for them to be able to get out of the classroom and do field studies."

In addition to its grant programs promoting environmental health science education in the schools, the NIEHS reaches the general population through its 25 NIEHS centers. The NIEHS requires each center to develop and maintain a Community Outreach and Education Program (COEP). Each center defines the community and/or region it serves and develops outreach efforts that are specific to the environmental health issues of greatest concern to that community.

For example, the COEP at the University of Texas Medical Branch (UTMB) offers a program called the Youth Environmental Studies Lab School, or YES! The program was designed to provide an intense, passionately taught, language-rich, small class environment to at-risk middle school children from the Galveston school system. At Central Middle School, all lessons in environmental science, math, reading, writing, and social studies coordinate around the environmental theme of

the week. Students study the environment in a pattern of concentric circles: their own neighborhood, Galveston Island, the county, southeast Texas, and eventually, by extrapolation, the natural world. In another UTMB effort, the Bench Tutorials program pairs high school students with a university graduate student, postdoctoral fellow, or faculty mentor for supervised instruction and research in field study on the molecular biology of asthma.

"I feel our educational efforts through the schools have been very successful," says Sharon Petronella, an assistant professor of pediatrics at UTMB. "We don't yet have a means of determining the impact of our educational programs on morbidity, but that may one day be possible. Last year, we conducted a survey of twenty thousand school kids in the Galveston area. The responses, including such information as number of days missed and reason for

groups such as the North Carolina Association of Biomedical Research. During the one-day workshops, teachers hear from NIEHS researchers about the latest developments in toxicology research and visit the institute's extensive lab facilities. They are provided with a curriculum titled *Chemicals, the Environment, and You* for use in the classroom. On average, the NIEHS sponsors two workshops per year attracting 40–50 teachers from the local area.

NIEHS also serves as a resource for programs at nearby universities and orga-



Education abroad. The NIEHS provides grants for environmental health education programs around the country. At Marion High School in New York (above), students test well water for fecal coliforms. The Bench Tutorials program in Galveston, Texas, (left) pairs high school students with graduate students, postdoctorate fellows, and faculty mentors to learn to conduct field studies of environmental toxicants such as air pollutants.



absence, may actually become a part of the students' school health record. We will be able to see where the health problems are."

Materials and resources developed by all 25 COEPs can be found at the COEP Resource Center (<http://www.apps.niehs.nih.gov/coeprc/>), a central repository of educational outreach materials produced by NIEHS grantees.

Opening Doors to the Future

The NIEHS conducts a variety of science education programs in and around its Research Triangle Park, North Carolina, campus. Prominent among these are annual teacher workshops cosponsored with

nizations that expose local high school and college students to possibilities for research and science careers. Students with, for example, the Research Apprenticeship Program developed by the University of North Carolina at Chapel Hill or Summer Ventures, a statewide program in which nearby North Carolina Central University participates, can visit the NIEHS campus, where they hear scientific presentations from institute staff, engage in informal discussions about career options and summer internship opportunities, and visit the laboratories.

Through its Summers of Discovery program, the NIEHS provides high school, college, and graduate-level students, science teachers, and college faculty with two- to three-month research internships in an NIEHS lab. Participants receive one-on-one mentoring with an institute scientist



Education at home. The BEST Program provides equipment and supplies to local public schools (above left). Through the Summers of Discovery program, students and teachers are invited annually to train in NIEHS labs. At the end of the summer, participants present their own research projects (right).

and attend weekly seminars where they discuss current research being conducted at the institute with the scientists in charge. At the end of the summer, students participate in a poster session at the NIEHS, where they make a brief oral presentation on their research and respond to questions as they would at a scientific society meeting. As a result of their internships, some students end up getting their names on peer-reviewed papers and/or being hired at the NIEHS.

Lessons for Learning

According to Johnson-Thompson, statistics show that by the third grade, girls and minorities tend to lose interest in science because of cultural expectations that they pursue other careers, and minorities in particular don't see any role models in science. One effort to break this trend is the Bridging Education, Science, and Training (BEST) Program, in which the NIEHS and the NIH partner with public schools in nearby Durham to nurture interest in environmental health science

among economically disadvantaged students.

Through BEST, the institute provides schools with surplus supplies and equipment. Staff members give presentations at schools, and act as mentors and science fair judges. And the NIEHS supports science-based programs in the public schools and hosts Durham students in mini summer internships, student research presentations, and awards programs.

Two of the schools in the BEST Program are C.C. Spaulding Elementary School and Shepard Magnet Middle School. C.C. Spaulding is designated as a Biosphere Magnet with a

Science, a National Science Foundation program that uses innovative, technology-enhanced curricula to teach scientific concepts and methods.

Another BEST experience points out what else is needed to successfully implement such programs. In 1996, the NIEHS worked with Durham's Hillside High School to construct a Molecular Biology Laboratory and Training Center. The institute loaned the school \$60,000 worth of state-of-the-art lab equipment, trained teachers in its use, mentored students, and provided judges for science contests. The center scored some notable successes early on, with several students winning area science competitions and performing summer internships at universities and corporations in Research Triangle Park.

But despite intensive financial and staff support from the NIEHS, the Hillside center has not proven to be a sustainable resource. According to Kenneth Cutler, former Hillside science teacher and now project director of the Berkeley,



curriculum that has a strong focus on the environment. The school features a Life Lab Biostation containing several live ecosystems, which promotes scientific thinking and learning. Shepard, meanwhile, served as a pilot site for teaching the national Biological Sciences Curriculum Study science curriculum, which teaches science in the context of themes and issues relevant to the students themselves. Shepard currently is participating in Technology Enhanced Learning in

California-based Project SEED (Summer Educational Experience for the Disadvantaged), too few students had the skills and experience necessary to take advantage of the lab. Cutler offers some lessons about introducing science education programs to high school students.

"In order for students to take advantage of a sophisticated science laboratory, they need to be prepared in the fundamentals—mathematics, reading, writing," Cutler says. "This needs to happen early,

well before they reach high school. Students especially need to know how to write in order to communicate their findings and to make presentations. Students should be encouraged to take higher-level courses to prepare them for scientific thinking and methodology. And they should be provided with paid summer research internships to keep them involved and motivated. Finally, you've got to have support for the program at every educational level."

Free for Teachers

Besides the institute's numerous funding opportunities, the NIEHS Office of Communications and Public Liaison produces educational booklets for use by school audiences and the general public. Students can use booklets such as *Environmental Diseases from A to Z* and *It's Your Scene, Teen* for a variety of in-class activities. The office publishes eight brochures aimed at K–12 audiences, covering such topics as common environmental hazards, genetic predisposition, environment-related diseases, and air pollution. Teachers can request up to 60 copies of each publication for free by calling 919-541-3345 or e-mailing the NIEHS at booklet@niehs.nih.gov.

Along with the formal educational programs sponsored by the institute, individual staff members devote countless hours to education-related activities. By all accounts, NIEHS scientists enjoy the opportunity to get out of the lab and interact with the public. Perhaps more importantly, they also consider it their responsibility to play a role in guiding the next generation of environmental health scientists and ensuring that students evolve into scientifically literate citizens.

"It's one of the more pleasurable things we do," says NIEHS senior investigator Jerry Yakel. "Students get really jazzed up by the science, and some of them do, in fact, end up pursuing careers in the field."

Over the last decade, science education activities at the NIEHS have positively impacted many lives across the nation, O'Fallon says. Through these activities, he says, students have won awards for academic performance in science, competed successfully for internships, and engaged in community-based activities aimed at improving local environmental conditions. Teachers have implemented engaging environmental health curricula in their classrooms. Communities have made policy changes aimed at improving the local environment. The result is a citizenry that better understands the connections between environment and health. **—John Manuel**

Headliners

NIEHS-Supported Research

Chemical Exposures and Childhood Leukemia



Parental Chemical Exposures and *ras* Mutations in Children

Shu XO, Perentesis JP, Wen W, Buckley JD, Boyle E, Ross JA, Robison LL; Children's Oncology Group. 2004. Parental exposure to medications and hydrocarbons and *ras* mutations in children with acute lymphoblastic leukemia: a report from the Children's Oncology Group. *Cancer Epidemiol Biomarkers Prev* 13(7):1230–1235.

A variety of carcinogens have been shown to induce *ras* mutations in animal and human tumor models, and *ras* proto-oncogene mutations have been implicated in the development of many malignancies including pancreatic and breast cancers. However, few data exist associating parental exposures and *ras* mutations in their children. Now a team including NIEHS grantee Leslie L. Robison of the University of Minnesota report that parents' chemical exposures may be associated with distinct *ras* mutations in their children with acute lymphoblastic leukemia (ALL).

This study used data from a large case-control study of childhood ALL conducted by the Children's Oncology Group in Southern California. DNA samples from the study children were examined for *ras* mutations. A total of 127 out of 837 ALL cases exhibited *ras* mutations in the K- or N-*ras* genes. Earlier studies have reported a 5–20% frequency of *ras* mutations among patients with ALL.

A number of parental chemical exposures were associated with significantly increased risk for *ras* mutation in the children. Use of drugs such as marijuana, LSD, and cocaine was associated with increased risk of N-*ras* mutation (three-fold higher risk for maternal use and two-fold higher risk for paternal use). Paternal use of amphetamines or diet pills was associated with a four-fold increase in N-*ras* mutation. Maternal exposure to solvents and plastics during pregnancy raised the risk of K-*ras* mutation about three-fold and seven-fold, respectively, and maternal exposure to plastics after pregnancy was associated with an eight-fold higher risk. Maternal and paternal exposure to oil and coal products and other hydrocarbons before and during pregnancy was associated with about a two-fold greater risk of N-*ras* mutation.

In previous studies, parental occupational exposure to hydrocarbons (such as chlorinated solvents, benzene, and paints) has been linked to elevated childhood leukemia risk. The present study has extended these findings to include drugs of abuse and additional chemical exposures, and to link them to *ras* mutations. The authors conclude that parental exposures to hydrocarbons and mind-altering drugs, chemicals that have been previously suggested to increase the risk of childhood leukemia, are related to specific *ras* mutations in childhood ALL. **—Jerry Phelps**

National Meeting Breaks the Mold

As the 2004 hurricane season nears its end after an unprecedented run of flooding and other water damage, attention is turning once again to the health effects of toxic mold infestation. Exposure to mold in residential, public, and commercial buildings is thought to have caused health problems ranging from bleeding lungs to hair loss—even to death. But debate continues over many key questions, such as how to best treat exposed individuals. In an effort to push through questions that still constrain the field, participants at the June 2004 National Meeting on Mold-Related Health Effects: Clinical, Remediation Worker Protection, and Biomedical Research Issues established a consensus on mold-related health effects and discussed clinical recommendations and a future research agenda for the evaluation, diagnosis, treatment, and management of these health problems.

The meeting was aimed at an interdisciplinary cross-section of policy makers, researchers, engineers, advocacy group members, and clinicians. Sponsors included the NIEHS, the Society for Occupational and Environmental Health, the Association of Occupational and Environmental Clinicians, the Johns Hopkins Bloomberg School of Public Health, the Urban Public Health Program of Hunter College, the University of Medicine and Dentistry of New Jersey School of Public Health, and the NIH Office of Rare Diseases.

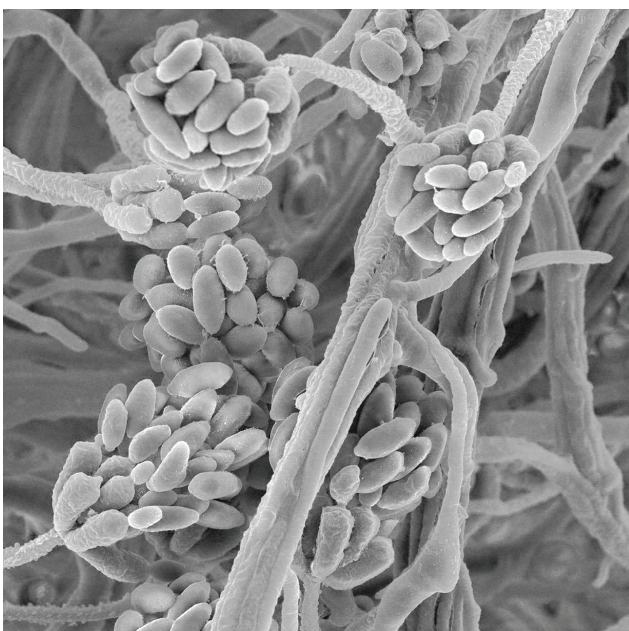
A Gamut of Questions

Outstanding research questions on the health effects of mold exposure run a broad gamut. Do airborne fungi produce known or unknown compounds that modulate immunity? Does co-exposure to multiple molds and other allergens occur, and how, and with what effect? Does mold exposure produce neurophysiologic and neurobehavioral abnormalities in children? And how can we best develop registries to chronicle exposures to mold and fungi?

One leading question is whether exposure to high levels of allergens in buildings triggers new-onset allergies. Some clinicians at the meeting had examined individual cases in which mold-contaminated environments appeared to have caused new-onset adult asthma, but population-based

research is needed to confirm these findings. Exposure in children seems to cause other respiratory tract disorders besides allergies. These include rhinosinusitis, cognitive and developmental effects, psychological effects, and other nonimmunologic health effects.

To study mold-related health effects, standard assessment tools such as clinical questionnaires for tracking symptoms and effects are needed, as are exposure assessment indicators. To date, questionnaires have proven valuable in assessing population response to abatement. But there are no good, clinically useful biological markers of exposure for nonallergic health outcomes, contended Clifford Mitchell, director of the occupational medicine residency



Public health menace. *Stachybotrys chartarum* hyphae is just one of many toxic molds whose spores can cause serious adverse health effects when inhaled.

program at the Bloomberg School of Public Health. Participants recommended that diagnostic testing be symptom-based and that exploratory tests for neurobehavioral, neurologic, immunologic, and allergic effects be developed.

Direct and indirect measures should be further developed and validated, said J. David Miller, an industrial researcher in fungal allergens and toxins at Carleton University. Markers of early biological effects might be related to cumulative exposures in moist or contaminated environments. Key questions presented by Michigan State University food scientist James Pestka included whether toxicokinetics and tissue concentrations in animals correlate with *in vitro* effects, and whether airborne exposure data or human tissue

levels correlate with thresholds for immune effects in animals. Participants produced a detailed list of research questions, which participants prioritized through a survey after the meeting. The list will be available in a meeting report due out this winter.

The Public Health Perspective

Without a consensus on specific aspects of mold-related health effects, the primary concern from a public health perspective is that affected people need to be treated and returned to a safe environment. In addition, the mold and the conditions that led to it need to be corrected.

It is difficult to measure people's exposures to molds, fungi, and their constituents and metabolic products from different sources. For example, many molds and fungi produce mycotoxins that further complicate health effects by acting in a synergistic fashion. Current techniques are limited in their sensitivity and what they can measure, especially given the wide distribution of fungi and complex aspects of growth and metabolism. Factoring in cumulative exposures and all clinically relevant exposures is beyond current capabilities. In general, large integrated samples are needed for accurate exposure assessment.

"The bottom line," explained Miller, "is that indoor exposure [involves] much more than just fungal material—it's a lot of stuff." And from a public health point of view, he said, what's most important is mitigating and treating the exposure. He acknowledged that the details—for example, knowing the biologically active agent or the specific spore present—may make a difference for policy makers, lawyers, and others.

Once a mold problem is identified, exposed individuals should first be removed from the exposure. Then they should receive treatment depending on symptoms and diagnosis using the tools of evidence-based medicine. Participants noted that treatment for cumulative and toxic exposures should be further researched; doctors do not currently advise prophylactic treatment based on known exposure alone, although symptoms, of course, are treated. The effectiveness of health and remediation interventions also needs probing. It is also important to clearly communicate with exposed populations after interventions to let them know what the exposure means to their

health and how to best manage it, Mitchell said.

Yet even after abatement, Mitchell added, some individuals may be symptomatic. "It's important for everybody to realize there is not a one hundred percent fix for [mold contamination and exposure], and this is a message that needs to go to the clinical world as well as the policy world."

Cleanup and Prevention

Many issues remain to be resolved around sampling. Generally, participants agreed that for home abatements, sampling is likely not worth the expense, and it makes more sense financially to just solve the problem. In large buildings (particularly office environments), on the other hand, sampling may be useful to pinpoint the source of exposure, both for legal reasons and for cleanup purposes.

But many remain skeptical of sampling's ultimate utility. "Sampling does little to add to the diagnosis, management, or correction of the problem," said Gregg Recer, a research scientist with the New York State Department of Health. And in practice, determining when a building is safe for individuals who experienced mold-related health problems remains a thorny issue. Most experts agree that visual and olfactory inspec-

tion by a competent authority with appropriate personal protective equipment before and after abatement is the best strategy.

Work is also needed in developing better guidance for maintenance and remediation workers. There are no standards or requirements for training, said Susan Klitzman, an urban public health professor at Hunter College. Some outfits offer certification, she said, but no hands-on experience—a component that experts at the conference felt was vital.

For now, there is a general consensus that, at a minimum, workers need some type of respiratory protection and gloves. "We can come up with general guidelines, but there's no one-size-fits-all approach," Klitzman said. "Professional experience and professional judgment are really paramount here."

Most of the existing guidance doesn't cover in sufficient detail other categories of workers who may work in an exposed area on a regular basis, such as maintenance workers, construction workers, teachers, and office workers. Participants will compile new guidance for all groups of workers as a product of the meeting. As Ted Outwater, a public health educator in the NIEHS Division of Extramural Research and Training, concluded, "We're into this

because we view workers as our first line of environmental defense."

As with many environmental threats, preventing exposure is key for mold; in this case, prevention largely involves correcting moisture problems and housekeeping deficiencies. Participants agreed that remediation goals should include addressing underlying moisture problems, removing or cleaning moldy and damaged materials, protecting workers and occupants, and using containment procedures appropriate for the conditions. Remediation techniques depend on moisture source, condition of the structure and furnishings, building materials, location of mold contamination, presence of additional contaminants, and effects on operations (for example, whether a business will have to be closed down for weeks).

"We have to think very carefully about [performing] outcome studies," said Mitchell. "At this point we certainly know enough that we have to correct the problem. And figuring out which part of the problem is most important to correct and what that question means for population health is an important research question." At the same time, he said, we need to understand how those corrective interventions pay off in terms of public health. —Julie Wakefield



Hunting Down Fugitive Literature

The first step to becoming a successful fugitive is to abandon all forms of conventional identification—driver's license, passport, checking account. People who stay out of the commercial realm are extremely hard to find. The same is true of literature. Libraries, with their online catalogs and helpful reference librarians, make it easy to find just about any piece of commercially published material. But lurking beyond the reach of the card catalog are thousands of materials such as reports, fact-sheets, newsletters, meeting transcripts, lesson plans, presentations, manuals, and interactive websites—so-called "fugitive literature"—that have never darkened the library's door. Today, some of those fugitives have been found: the COEP Resource Center website (<http://www-apps.niehs.nih.gov/coeprc/>) offers visitors a bibliographic database for searching and reading about more than 600 environmental health materials developed by the Community

Outreach and Education Programs, or COEPs, associated with each of the 25 NIEHS centers.

Since 1996, when the NIEHS established COEPs as an essential component of its Core Center Program, NIEHS grantees have been generating large volumes of fugitive literature. Charged with increasing public understanding of environmental health science research, the 25 COEPs carry out diverse projects. They host public forums and town meetings, offer professional development opportunities to teachers and health care providers, bring students to their laboratories for tours and summer science camps, and arrange for scientists to give presentations at local

schools. They also develop curricula on environmental health for students in kindergarten through twelfth grade. These curricula are based on the latest research and are designed to meet state and national education standards.

The documents created during the course of the COEPs' activities represent a wealth of environmental health information, innovative ideas, creative teaching approaches,

lesson plans, videos, posters, brochures, training manuals, and successful outreach strategies. These materials are usually free and ready to use in a variety of education and outreach settings. However, until recently the people who could most use them—teachers, parents, nurses, community groups—were unlikely to find them.

That changed in 2000, when the NIEHS developed the COEP Resource Center to col-

lect and catalog the products of the COEPs' projects. Today, most printed resources are available for download in PDF format, and the database provides an abstract and ordering information for nonprint materials such as videos and CD-ROMs. The site

also posts information about upcoming events, news, related links, and contact information for each COEP grantee.

The COEP Resource Center is now expanding its scope by incorporating materials produced by grantees in several other NIEHS programs besides the Core Center Program. Additions are planned over the next few months. —Karyl R. Colopy



Sister Study Launched Nationwide

Breast cancer is the second most commonly diagnosed form of cancer among U.S. women, according to the National Cancer Institute (NCI), and the second leading cause of cancer deaths in this group. For the year 2003 alone, the NCI estimated more than 212,000 new diagnoses and more than 40,000 deaths from breast cancer. A woman's risk increases with her age: breast cancer is the most common cause of cancer death after age 65, and nearly half of all breast cancers are found in this age group—a figure that is likely to increase significantly as baby boomers age into the next decade. Plus, black women have the highest death rates from breast cancer. To address these concerns, the NIEHS-sponsored Sister Study plans to explore on a nationwide basis, beginning in October 2004, how genetic and environmental influences may work together to cause breast cancer.

The study has been in development since 2001 and under way in pilot form for the past year. A total of 50,000 female volunteers aged 35–74 whose sisters have been diagnosed with breast cancer will be recruited and receive health evaluations over a period of 10 or more years. First-degree relatives, including sisters, have about twice the risk as the average woman of developing breast cancer.

Past studies have focused on pesticides, solvents, and electromagnetic fields as possible contributors to breast cancer, but have failed to find consistent links to the disease. Study authors Dale Sandler, chief of the NIEHS Epidemiology Branch, and Clarice Weinberg, chief of the Biostatistics Branch, believe this study—unlike past studies—will be able to effectively characterize levels of a participant's environmental exposure prior to onset of cancer, a feat that can't be accurately accomplished retrospectively.

Recruiting began in fall 2002 for a pilot phase in four cities—Phoenix, St. Louis, Tampa, and Providence—involving a total of 2,000 participants. “We wanted to go slowly at first,” explains Sandler. The pilot phase gave the researchers time to fine-tune recruiting strategies and data collection methods, arrange for field staff training, and streamline the lengthy questionnaire. The original four cities

were chosen for their economic, ethnic, and geographic diversity, Sandler says, and by early 2004 the study spread beyond city limits to encompass the entire states of Arizona, Missouri, Florida, and Rhode Island. In August the study also began recruiting in Illinois, Ohio, Virginia, and North Carolina.

Getting adequate participant diversity is important, Sandler says. She believes the study results will be useful to all U.S.

women only if a diverse cross-section of women participate. “With a diverse population, we will have a wider range of [health and environmental] exposures, increasing our ability to detect associations,” she says.

The original eight states were chosen in part because they had community- and church-based breast cancer awareness programs, heavy minority interest, and what Sandler pragmatically terms “good connections” in both public and private sectors. “Our contacts in the breast cancer advocacy community help with grassroots recruitment,” she says.

Participants receive a welcome kit by mail with instructions on how to prepare for the study. A staff member calls first to walk the participant through the kit and later to conduct the survey, which takes about two hours. Next, independent phlebotomists working under contract to the NIEHS make home visits to draw blood samples, collect household dust samples and toenail clippings, and take blood pressure, weight, height, and body measurements.

“Even though it's an enormous national study, we're doing everything we can to make it as personal as possible,” Sandler says. “We want to make sure that the women get something back, thus we have a duty to let them know what we learn from the study. We plan to contact them regularly over the years with news from the study.”

Sandler and Weinberg will closely evaluate the expected 1,500 women who will develop breast cancer within five years of the study's start, analyzing environmental, genetic, and health data captured from the very beginning. “We've learned what works [in terms of study design and implementation], and what doesn't,” Sandler says. “We're ready.” —Jennifer Medlin



Sisters are doing it for themselves. The Sister Study, now recruiting nationwide, will yield new information on how genes and environment may interact to cause breast cancer.

For More Information

<http://www.sisterstudy.org/>