

## New Study Shows 22% of Pregnancies Lost Before Clinical Detection

By Hugh Lee

A new study has revealed surprising findings about the processes of early pregnancy. Using an ultrasensitive pregnancy test, scientists at the National Institute of Environmental Health Sciences have found that one-third of embryos reaching the womb fail to survive, with most losses occurring before women realize they are pregnant. These results were reported in the July 28 issue of the *New England Journal of Medicine*.

This study was designed by Dr. Allen J. Wilcox, epidemiologist at NIEHS, as part of a program to explore the effects of environmental hazards on human reproduction. About 15 percent of all recognized pregnancies are known to end in miscarriage. Epidemiologists have shown that the risk of miscarriage is increased by a woman's smoking or occupational exposure to certain hazards. However, it has long been suspected that there are more pregnancies lost even earlier, before they are clinically apparent. These earlier losses might also be vulnerable to environmental exposures. The purpose of the NIEHS study was to develop a method for measuring very early loss as a new and sensitive way to detect reproductive hazards.

Wilcox recruited more than 200 healthy  
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## NIH Grantees Win Presidential Honors

Ten NIH grantees were among the 30 recipients of the National Medal of Science and National Medal of Technology, the nation's highest honors for achievement in mathematics, science, engineering, technology and social sciences. President Reagan made the awards recently at the White House.

Among the winners of the 1988 National Medal of Science were:

Konrad E. Bloch, professor of biochemistry emeritus at Harvard University, who was honored for his discovery of the principle of suicide inhibitors for enzymes (substances that cause the enzyme to self-destruct) and for an example of that principle. His discovery points the way to the rational design of therapeutic agents. Bloch received 46 grants totaling more than \$5 million, chiefly from NIGMS and NHLBI, during the period 1962-1986.

Michael S. Brown and Joseph L. Goldstein, professors of medicine and genetics at the University of Texas, were cited for their historic discovery of the basic mechanisms controlling

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# The NIH Record

*Completion Seen Next Summer*

## Ground Broken for Children's Inn at NIH

It was hard to tell which was higher, the hope or the humidity, as pediatric patients from the Clinical Center broke ground for the new Children's Inn at NIH on July 29.

A dozen youngsters grabbed spades to inaugurate construction of the 32,000-square foot residence that will be home for up to 36 patients participating in NIH research and their families. Completion of the project, located on several wooded acres near the corner of West Drive and Cedar Lane, is expected by next summer.

The groundbreaking culminated years of

effort on the part of NIH employees, concerned members of the community, politicians and Merck & Co. Inc., which donated more than \$2 million for construction of the Inn.

"This is a day for all of us to lift up our hearts and rejoice," said Cindy White of Scalp, Pa., whose daughter Katie has been a cancer patient at NIH since 1983. "This is part of the fulfillment of the American dream and the beginning of a dream come true."

As if the fear and confusion wrought by the

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"Thanks a million—here's the first downpayment," said Dr. P. Roy Vagelos (l), chairman and chief executive officer of Merck & Co. Inc., as he presented a million-dollar check to former NCI patient Brenda Small. Small and NIH pediatric patients signed the drawing of the Children's Inn seen at rear and presented it to Vagelos as a memento. Looking on is Carmala Walgren, who worked hard to make the Inn a reality.

## 'Bo-Tox' Banishes Symptoms

## Treatment at NINCDS Gives Adults Free Speech Again

By Elizabeth Gillette

To an Atlanta trial lawyer in his forties, the speech disorder was devastating. He could no longer speak without cutting off words at midpoint, and he lost control over the pitch of his voice so that he seemed to be always on the verge of crying. During 6 years of suffering, his life of law began to unravel. He lost cases and clients. Finally, he considered a career change out of the courtroom where winning or losing would not depend on his voice.

Fortunately for the lawyer and for other men and women like him who develop the

debilitating speech disorder known as adductor spasmodic dysphonia (SD), a new treatment may help them speak normally again. Pioneered by researchers at NINCDS, the treatment consists of periodic injections of a small amount of botulinum toxin into muscles of the larynx that control the vocal cords.

"I've never had such a transformation (in patients) with such terrific results," Dr. Christy Ludlow, NIH speech pathologist and

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## AWARDS

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cholesterol metabolism, opening the way to a new pharmacologic approach to the treatment of cardiovascular disease, the leading cause of death and disability in the Western world. Brown held 12 grants, mainly from NHLBI, totaling \$1.57 million from 1970 to 1978. Goldstein got his first grant of \$750 from NIH in 1965 and by 1987 had received a total of 29 grants for almost \$12 million, mainly from NHLBI and NIGMS.

Stanley N. Cohen, professor of genetics and medicine at Stanford University, was hailed for his discovery of methods for propagating and expressing the hereditary information of DNA introduced into living cells, thereby enabling the cloning of individual genes and the study of their structure and function. He has held 70 grants worth more than \$11 million, mainly from NIAID and NIGMS, beginning in 1966 through the present.

Maurice R. Hilleman, director of the Merck Institute for Therapeutic Research, was honored for his brilliant discoveries in basic research and ingenious inventiveness in creating vaccines that are the foundation for control of infectious diseases through immunologic intervention, preventing death and disability in millions of persons worldwide. He received 36 grants totaling more than \$10 million during 1968-1980, all from NCI.

Eric R. Kandel, professor of physiology and psychiatry at Columbia University, was cited for discovering the first cellular and molecular mechanisms contributing to our understanding of simple learning and memory and providing a stimulus to research which promises to lead to dramatic advances in our understanding of mental processes. From 1962 through 1986 he received 61 grants totaling more than \$7 million from NIMH, NINCDS, DRR and NIGMS.

Rosalyn S. Yalow, professor at Mt. Sinai School of Medicine and at Albert Einstein College of Medicine, was cited for her historic contributions to the discovery and development of radioimmunoassay, a technique that employs radioactive isotopes to detect and measure the levels of insulin and hormones in the blood and body tissues. She received one grant for \$142,500 from DRR in 1982.

Elias J. Corey, professor of chemistry at Harvard, was saluted for his strikingly original contributions to organic synthesis, which have brought the science of organic chemistry to a new level of power and precision. From 1962 through the present he has received 49 grants worth more than \$9.5 million from NIGMS, NCI, NIAID, DRR and NHLBI.

Among those who won the 1988 National Medal of Technology were Raymond Damadian, chairman of FONAR Corp., and Paul C. Lauterbur, director of the Biomedical Magnetic Resonance Laboratory at the University of Illinois, for their independent contributions in conceiving and developing the application of magnetic resonance technology to medical uses including whole-body scanning and diagnostic imaging. Damadian held 19 grants worth some \$873,000 in the years 1962-64 and 1970-77; granting institutes included NHLBI, NIAMS, NCI and NIGMS. Lauterbur has received 29 grants totaling \$3.37 million in the period 1972-1986; funds came from NIMH, NCI, NHLBI, DRR, NIGMS.

In 1959, Congress authorized the president to award the National Medal of Science to individuals who deserve special recognition for their contributions to knowledge in the physical, biological, mathematical, engineering, behavioral, or social sciences. Selection is based mainly on the impact of an individual's work on the current state of a given field. Unusually significant achievements are considered in relation to their potential effects on the development of scientific thought.

The National Medal of Technology was established by Congress in 1980 to give presidential recognition to individuals or companies for outstanding contributions to improving the well-being of the nation through the promotion of technology or contributing to a work force skilled in applications of advanced technology and manufacturing processes. All told, the 10 NIH grantees received more than \$61 million spread over 352 separate awards. □



*Dr. Judith H. Greenberg has recently been appointed director of the Genetics Program, NIGMS, which funds research and training on fundamental genetic processes and the mechanisms of inheritance in health and disease. Among the program's areas of interest are how genetic information is transmitted and expressed, how gene expression varies within populations, and how genes direct development. Since 1985, she has been deputy director of the program.*



*Dr. Susan S. Ellenberg has been appointed chief of the newly created Biometrics Research Branch of the AIDS Program, NIAID. The branch will provide statistical collaboration for clinical trials of AIDS treatments and vaccines, epidemiologic studies and strategies for drug and vaccine development. In addition, it will focus on statistical issues in the study of AIDS, and develop programs to encourage such research in the biostatistical community. Ellenberg came to NIH in 1982, joining the Biometric Research Branch, NCI.*

# The NIH Record

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NIH Record Office  
Bldg. 31, Room 2B-03  
Phone 496-2125

Editor  
Richard McManus

Staff Writers  
Anne Barber  
Carla Garnett

Editorial Assistant  
Marilyn Berman

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DCRT, Joan Ackerman  
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## Children of Exposed Mothers Show Contaminants

By Hugh Lee

Polychlorinated biphenyls, or PCB's, synthetic chemicals notorious as environmental contaminants, have long been known to be retained in human body fat. A recent study shows that Taiwanese women who were exposed to contaminated cooking oil have passed on to their unborn children part of the contaminants.

Cooking oil in Taiwan contained both PCB's and contaminants of PCB's called dibenzofurans. Children of the exposed women showed physical health effects as well as marked delays in behavioral and intellectual development. None of the children actually consumed the contaminated cooking oil, and some of them were affected years after their mothers were exposed.

The delayed effects on the children have been clinically identified and quantified in a study sponsored, in part, by the National Institute of Environmental Health Sciences and featured in the July 15 issue of *Science*. Lead author of the article, Dr. Walter J. Rogan, chief, Epidemiology Branch, NIEHS, is a specialist in preventive medicine.

The study involved clinical examination during 1985 of 117 children born to women who ingested contaminated cooking oil between December 1978 and May 1979. The study also examined 108 children of mothers not exposed to the oil for comparison.

Children of exposed mothers were shorter and weighed less than their peers, and more often had abnormalities of their gums, skin, and nails. Some were born with chloracne, a severe acne typical of chlorinated hydrocarbon exposure. Also, the abnormal presence of teeth at birth was more common among children of exposed mothers, as were lung problems including clinically diagnosed bronchitis.

The study notes that the half life, the length of time the human body requires to clear half a given quantity of contaminant after it enters the body, of dioxins (chemicals similar to the PCB's) is about 7 years. This indicates that children of exposed mothers were exposed transplacentally to PCB's and PCB contaminants stored in the mothers' body fat years after the exposure to the mothers had stopped.

In addition to the physical health effects, researchers detected clear delays in the children's developmental behavior and intellect. Rogan said, "The exposed children were delayed, compared to controls, in the age at which they performed tasks such as saying phrases and sentences, turning pages, carrying out requests, pointing to body parts, holding pencils, imitating drawn circles, or catching a

ball." Development of speech was delayed in 7 percent of the exposed children as compared with 3 percent of the controls.

"These findings are most consistent with a generalized disorder of ectodermal tissue in the fetus, the tissue from which the skin, nails, nervous system and sense organs, among others, arise," Rogan said. "This syndrome is one of the very few documented to result from transplacental exposure to pollutant chemicals."

Coauthors of the study included clinicians and public health officials in Taipei, Taiwan, as well as researchers in the U.S. □



Dr. Jon Lewis, facility director, uses the recently dedicated intermediate voltage microscope, supported by the Division of Research Resources, at the Bowman Gray School of Medicine in Winston Salem, N.C. Core research emphasis at the national resource center called MicroMed, is on atherosclerosis, microbiology and immunology, pediatrics, and biochemistry.

## R&W Has Discount Tickets

R&W has a limited number of discount tickets to the following events:

*Sleuth*, Kennedy Center, Aug. 25; National Symphony, Kennedy Center, Sept. 16; *Shear Madness*, Kennedy Center, Oct. 6; Moscow Circus at the Patriot Center, Oct. 21.

In addition, R&W has discount tickets to Roth and KB movie theatres, Kings Dominion, Busch Gardens, Wild World, Colonial Williamsburg, and more.

For more information or to purchase tickets, stop by or call the R&W Activities Desk, Bldg. 31, Rm. B1W30, 496-4600. □

## Viral Cause of Alzheimer Disease Postulated

By Claire McCullough

After 20 years of research, evidence that Alzheimer disease (AD) may be caused by an infectious agent has emerged. With grant support from NIA and NINCDS, researchers at Yale University appear to have successfully transmitted a blood-borne virus from humans to laboratory animals. The agent, which results in a fatal brain disorder, produces brain pathology similar to that caused by Creutzfeldt-Jakob disease (CJD), a rare, progressive brain disease.

The research team, led by Dr. Elias E. Manuelidis, studied one known AD patient and 10 healthy members of families in which at least two close relatives had Alzheimer disease. White blood cells drawn from these persons were homogenized and then inoculated into the brains of hamsters.

Within 1 year of inoculation, material from five of these persons resulted in the development of characteristic CJD pathology in the hamsters. To verify the results, a second series of hamsters was reinfected with brain tissue from three of these people. In all instances, the animals who received the second series not only developed the disease, but contracted a more severe and rapidly progressive form

When asked why this study succeeded when all previous attempts to transmit Alzheimer disease had failed, Manuelidis explained, "Prior experiments were undertaken with tissue from persons in advanced stages of Alzheimer disease. Since the titer (strength) of a virus can be very low at the end stages of disease, we decided to check the infectivity at early or preclinical stages of the disease."

Because Alzheimer disease is unique to humans, there is no animal that can serve as a suitable model for studying the disease. This may explain the lack of AD-type changes in the infected hamsters. If an infectious agent exists in the general population, the authors speculate that factors either in the environment or within the body itself (e.g., immunity or genetics) could trigger the onset of dementia disease. An increasing number of investigators believe that several coexisting factors may be necessary to produce Alzheimer disease.

Due to the preliminary nature of these results, additional research is necessary to confirm the Yale findings. These findings may indicate that at least some cases of Alzheimer disease have an infectious origin, providing a key to understanding this baffling disorder. □

## PREGNANCY

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women who were planning to become pregnant. These women were enrolled into the study at the time they stopped using birth control. Volunteers collected daily urine specimens for up to 6 months, providing a total of nearly 30,000 specimens. Urines were then shipped from NIEHS headquarters at Research Triangle Park, N.C., to Columbia University in New York City, where they were assayed for the pregnancy hormone hCG. The hCG assay, developed by Columbia scientists, is up to 100 times more sensitive than conventional assays, which are able to detect less than one ten-billionth of a gram of hCG in a milliliter of urine. With this assay, hCG can be detected about a week after fertilization, which is about the time that the fertilized egg is beginning to attach itself to the wall of the womb. Twenty-two percent of pregnancies detected by this hCG assay were lost in what seemed to be an ordinary menstrual period, without being clinically recognized. When recognized miscarriages were included, the total pregnancy loss was 31 percent.

Another notable finding was that the women who had early losses usually became pregnant again soon after the loss. Most of those subsequent pregnancies ended in live birth. So instead of being a sign of infertility or other problem, the early pregnancy losses in this study were events that occurred mostly among women who conceived easily. Further work will be done to see whether the risk of loss was related to possibly hazardous exposures, such as alcohol or caffeine consumption.

Wilcox had been advised at the onset of the study that it would be hard to recruit women willing to collect daily urine specimens. "As it turned out, the main problem was finding women before they stopped their birth control. Once women volunteered, they did superbly," he said. "These women provided urine specimens for 98 percent of their days in the study." Wilcox said that much credit went to the skill and sensitivity of the field workers, who interviewed the volunteers and picked up specimens.

Another primary factor in the success of the study was early consultation with the National Institute of Child Health and Human Development. "We got world-class advice from our sister institute within the National Institutes of Health on methods for detecting early pregnancy," Wilcox said. Much of the support for Columbia's development of the hCG assay had originally come from NICHD.

Wilcox gave special credit to Drs. Clarice Weinberg and Donna Baird of NIEHS and

Dr. Robert Canfield of Columbia University. "This study was a marriage of epidemiology, biostatistics, endocrinology and biochemistry. I've been lucky to have absolutely top-notch colleagues," he said.

Having established this method to measure early pregnancy loss, Wilcox now plans to apply it in a study of occupational exposures. Several groups in the U.S. have already adapted Wilcox's methods for their studies of working women. For his next project, he is working with scientists in the People's Republic of China on a proposal to study factory workers in Shanghai. "Our ultimate hope is that studies of early pregnancy loss will help us to detect the environmental hazards that interfere with successful pregnancies and healthy babies," he said. □

## NHLBI Seeks Volunteers

The Hypertension-Endocrine Branch, National Heart, Lung, and Blood Institute, is seeking patients with obesity and hypertension to be enrolled in a 12-week program to evaluate the effects of dietary weight reduction, without medication. Patients will continue to be followed in association with their primary physicians.

If you are overweight (more than 15 lbs. over ideal body weight), with diastolic blood pressure exceeding 90 mm Hg, but without diabetes or kidney failure, call Joan Folio or Dr. James Chan, 496-3244. □

## Lab Help Sought at USUHS

Looking for someone with some experience in solid tumor tissue handling to work a few hours per month, spread out over 1 year. Salary negotiable. Tissue culture and animal experience desirable, but not necessary. Contact Dr. Dachman, 295-3145 or 576-1939. □



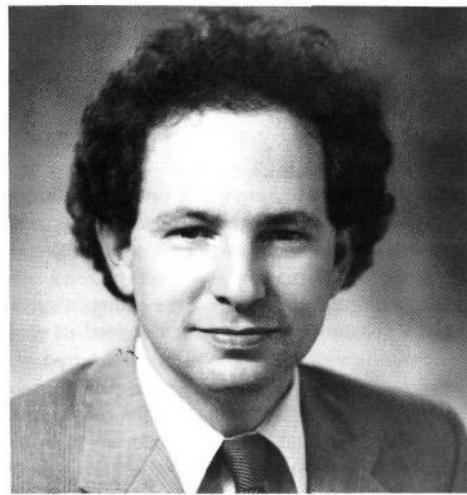
Seventh-graders Jennifer Johnson (l) and Jenelle Moore of Colorado Springs, Colorado, thought DRS information officer Jim Doherty (c) helped a lot to get them into the 1988 National History Day final competition at the University of Maryland recently. So they invited him to come to College Park to see their exhibit, including the things he had sent them for it. Early this year, Jennifer and Jenelle decided to make an exhibit on "Veterinary Medicine: Yesterday, Today, and Tomorrow" for the competition. Some weeks later they were becoming discouraged because they had received no replies to their letters requesting information from various organizations. Then they received a packet from NIH containing pictures and information on laboratory animal medicine and the great increase of women veterinarians in PHS agencies during the 1980's. Doherty had sent it in reply to their letter to DHHS. In May, Jennifer's mother, Sue Johnson, wrote Doherty, "The pictures you sent became the focal point of their blackboard and gave them the encouragement they needed to approach local veterinary hospitals to schedule tours and interviews." Jennifer and Jenelle's exhibit won prizes in the local, regional, and state contests, so they were on their way to College Park and Washington, D.C. The final contest? No prize, alas, but a rating of "Superior."

## **Paul Succeeds Goodwin as Director of IRP, NIMH**

Dr. Steven M. Paul, chief, NIMH Clinical Neuroscience Branch, has been appointed acting director, Intramural Research Program, by Dr. Lewis L. Judd, institute director. Paul succeeds Dr. Frederick K. Goodwin, recently named administrator of the Alcohol, Drug Abuse, and Mental Health Administration.

Since founding the branch in 1982, Paul has directed an interdisciplinary program of basic and clinical research into the neurobiological mechanisms underlying anxiety, depression, schizophrenia, appetite and obesity.

He first came to NIMH in 1976 as a research associate in the neurochemistry laboratory of Dr. Julius Axelrod, the institute's Nobel laureate. In 1978, he joined the staff of



*Dr. Steven M. Paul*

the Clinical Psychobiology Branch which was then under Goodwin's direction.

A native of Chicago, Paul received his B.A., M.S. and M.D. degrees from Tulane University. He interned in neurology at Charity Hospital, New Orleans, and did his psychiatric residency at the University of Chicago Pritzker School of Medicine. He has academic appointments at the Uniformed Services University of the Health Sciences, University of Maryland School of Medicine, and the Medical College of South Carolina.

He is a board-certified member of the American Board of Psychiatry and Neurology and a Fellow of the American College of Neuropsychopharmacology. □

## **NIEHS Sponsors Conference on Aquatic Food and Cancer**

In certain locales, important food fishes have a high prevalence of irregular cell growths called neoplasms. Edible portions of some food fish contain measurable, although small, quantities of known carcinogens or cancer promoters. The National Institute of Environmental Health Sciences will sponsor a conference to allow scientists to share information on these kinds of observations. The conference, titled "Chemically Contaminated Aquatic Food Resources and Human Cancer Risk," will be held Sept. 29-30, at the NIEHS Conference Center, Bldg. 101, in Research Triangle Park, N.C.

Scientific investigators from throughout the United States and Canada will present studies on such topics as the incidence of neoplasms and pre-neoplastic lesions in food fish; the extent of carcinogen contamination, metabolism and reactivity in edible tissues; and the factors determining the magnitude of human risk. The conference will conclude with an assessment of research needs, methods and priorities.

NIEHS has taken a leadership role over the years in assessing the environmental contaminants in aquatic species and their potential impact on human health. In addition to the institute's long-term basic research program by staff scientists within what is now the Laboratory of Cellular and Molecular Pharmacology, NIEHS has supplemented the program through additional research at satellite facilities in Maine and Florida. The NIEHS has also established five Marine and Freshwater Biomedical Science Centers through funding

administered by its Division of Extramural Research and Training.

Aquatic species serve as biological models, allowing researchers to learn more about biological processes within the human body. Aquatic species also serve as indicators of levels of pollution when the concentrations of contaminants are measured in such animals. This conference will focus specifically on aquatic species in the human food chain, and how environmental agents are taken up, metabolized, and/or stored in the bodies of edible aquatic species.

NIEHS director Dr. David P. Rall, who initiated the marine and freshwater research programs at NIEHS, said that the increasing North American appetite for seafood makes a sensitivity to preserving the healthfulness of seafood important.

"As we try to reduce our intake of fats by increasing our intake of fish as a main course, we must be more and more alert to the dimensions of health that this changed diet involves," Rall said. "We need the knowledge to protect this excellent source of low-fat protein."

The conference is open to the public at no charge for registration. However, because of space limitations, advance registration is recommended. Upon receipt of your registration material, information on transportation and local hotel accommodations will be sent. For registration material, contact: Martha Taylor, Mail Drop A2-03, NIEHS, P.O. Box 12233, Research Triangle Park, N.C. 27709, or telephone (919) 541-3506.—Hugh Lee □



*The medical/pathological (MPW) waste box, sometimes called a "burn box," has been redesigned by the Division of Safety to identify clearly waste destined for incineration on campus. Correct labeling of MPW and radioactive waste streams is required by the Nuclear Regulatory Commission to prevent crossover between the two types of waste. An added benefit of proper labeling is that waste handling personnel will know what to do in the event of a spill or leak from the boxes.*



*Dr. Allan M. Weissman recently received the Clinical Research Trainee Award at the meeting of the American Federation for Clinical Research in Washington, D.C. He is a senior staff fellow in the Cell Biology and Metabolism Branch in the Intramural Research Program of NICHD.*

## INN

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serious illness of a child were not difficult enough, parents who bring their youngsters to NIH for treatment must also cope with an entirely new environment and, perhaps most difficult, a lack of control over what happens to them and their loved ones, White said. The Inn will relieve a large portion of the stress experienced by families that typically come long distances to Bethesda for treatment.

"Living in a home can work wonders to bolster the hope and determination of a child," White said. "From each other the children will gather strength and buoy each other up. The Inn will be the next best thing to being home."

At the moment, children treated as outpatients at the CC typically remain in local motels for the duration of therapy. Pediatric health professionals at NIH have long known the burdens these families face—travel to and



Dr. Philip Pizzo, chief of NCI's Pediatric Branch, addresses the crowd while his wife Peggy, a child advocate and public policy specialist, looks on.

from Bethesda, limited opportunities to socialize, isolation from community and inadequate quarters. The Inn will enable families to live in close proximity to one another and will be free of charge.

"The Children's Inn will not solve the stresses of illness," said Dr. Philip Pizzo, chief of NCI's Pediatric Branch and a longtime proponent of a home for young NIH patients and their families. "But it will provide respite, care and compassion. It will stand as a symbol of our commitment to the care and healing of the whole child and the preservation of the whole family."

"The creation of this Inn has been a family affair, right from the beginning," said Dr. William Raub, NIH deputy director. "We share the single goal common to all families—that children grow up happy and healthy and lead productive lives."

If the events leading to the groundbreaking can be called a family affair, then Washington attorney Carmala Walgren may be considered

a godmother. She learned of the need for a children's home at NIH when her family's babysitter was treated for cancer here several years ago. Determined to provide help to the families she saw struggling to cope so far away from home, Walgren, wife of Rep. Doug Walgren of Pennsylvania, used an extensive network of friends and associates to make the Inn a reality.

"This project is a big dream," said Rep. Walgren. "It started with Phil Pizzo and his wife Peggy" and extends to more than 50 members of the House and Senate, both Republican and Democrat. Rep. Jim Wright, speaker of the House of Representatives, and his wife Betty are honorary co-chairs of the Inn, along with Reps. Peter Rodino and Silvio Conte, he said.

"The greatest contribution of all, however, is by Merck," Walgren continued. "The gift of more than \$2 million is a tremendous testament to the commitment of Merck and its chairman, Roy Vagelos. The Inn will serve to remind us that the most important thing in caring for the person in medicine is caring for the person."

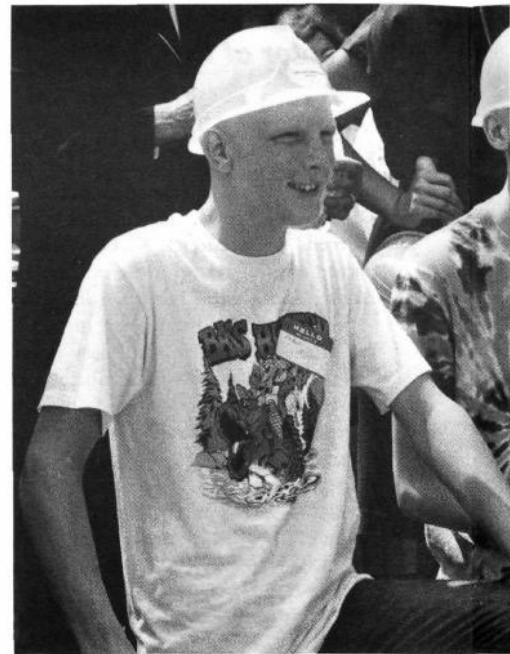
Dr. P. Roy Vagelos, chairman and chief executive officer of Merck, spent 10 years on the NIH campus as a researcher and knows the campus well. "In fact, I used to spend evenings looking after children here," he said. "It's really terrific that only 3 months ago we unveiled plans for the Children's Inn and today we are breaking ground. We at Merck are just the support troops, though. We can't wait for the building to be ready."

Supervising construction of the country-style home will be Washington area builder Alan Kay, a prominent philanthropist who has long favored the American Cancer Society.

"We've been in the building business for 30 years and have done hundreds of millions of dollars worth of construction," he said. "The Inn is the smallest project we've ever done, but it is also the one we have been most proud and most privileged to do. Everyone on



Michael Pizzi, an occupational therapist in the CC Department of Rehabilitation Medicine, led a choir of youngsters that included Andrea Williams.



Nathan Meyer (l) and Roger Hall make a pair of reso-

our staff rallied around this project—I only wish they would do the company's work with as much dedication as they showed on this one."

Uncommon devotion to the project's success was a common trait of those involved in creating the Inn. Among the most committed was child advocate Peggy Pizzo, wife of Philip Pizzo. She had three messages for the large audience that had gathered under an open tent for the groundbreaking: "To parents I would say, 'You are not alone.' We stand with you as you fight for your children's health." To NIH, Merck and others who made contributions, she said, "Thanks for helping us to realize this dream, and for embracing it as your dream too." Lastly, she assured everyone that there are many ways to help families facing serious chronic illness. Among the avenues is donations to the Friends of the Children's Inn at NIH, a volunteer organization that is raising the \$2 million needed to furnish the Inn once it is built.

Wrapping up the speeches was a moving account of her struggle to overcome cancer given by Brenda Small, a former patient at NIH. Diagnosed as hopelessly ill with rhabdomyosarcoma at age 11, Small has progressed to the point that now, at age 18, she is already a licensed practical nurse and has been accepted to Johnson C. Smith College in Charlotte, N.C., on a full basketball scholarship; she intends to study medicine.

Reading from a poem about her illness



of resolute spadesmen at the groundbreaking ceremony.

called "I Know," Small said, "No, you're not alone, we've faced the same foes. Here are a few words of encouragement from someone who knows: Many will follow after; there's been many before, and for every tear you've shed I've shared thousands more. Yes, I know what you're feeling because I've been there too. But I made it through somehow and so will you . . . —Richard McManus



Brenda Small survived a long and serious bout with cancer at NIH and will attend college this fall on full scholarship.

## A Home Away from Home

To the patients and their families located on 13 West of the Clinical Center, home of NCI's Pediatric Branch, the Children's Inn at NIH is viewed as an extension of the caring that is already being provided at NIH.

Gale Larkey, mother of patient Hillary McCabe (age 15) says, "The senior medical staff and nursing staff are so exceptional in their caring that they have worked so hard for this Inn. It is their concern for not just the patient but for the family as well."

McCabe has been coming to NIH since last September and sometimes stays for up to 3 months. Her mother always accompanies her and stays for the entire length of the visit, no matter how long.

"When the Inn is completed, I will be able to bring my family for support," Larkey says, "but, for now, it is just me and Hillary."

McCabe and her mother are from Miami, Fla., and saw their first snow last winter. "I didn't get a chance to play in it, though," she said.

McCabe will be going to Camp Fantastic, the summer camp for kids with cancer, for the first time this year and doesn't really know any kids going. With the addition of the Inn, she says, "I'll have a chance to know and interact with other kids like me. It will be more like a home environment."

The Meyer family of Wauseon, Ohio, will be especially delighted to see the Children's Inn completed. Nathan Meyer, 15 years old, comes to NIH every 3 weeks; the average visit lasts about a week. His mother, Alvena, comes with him, sleeps in his room, does laundry as best she can, and eats all her meals in the cafeteria.

"Once we were here for 3 months at a motel. Nathan was an outpatient coming in for radiation therapy; we would come in, get treatment and then go right back to the motel."

Only one member of the family is allowed to stay in the hospital room, so when Nathan underwent surgery last year, his mother and father stayed at a motel for a month. "My husband and I rotated being here with Nathan, but with leaving late at night and exchanging places, we did not get a lot of rest," Alvena said.

Transportation will also be a lot easier, she continued. "Now, if you have an early appointment on a Monday morning, you take the shuttle to NIH, a taxi to the motel, and then a taxi back again the next morning. The Inn will certainly be timesaving as well."

Nathan enjoys making models and was busy  
**(See HOME, Page 8)**



Hillary McCabe, a cancer patient from Miami, "can't wait for the Inn to be completed." Although her protocol is nearing completion, she feels she will get to stay at least once at the Inn.

Photos: Ernie Branson



"The Inn will add real life and well-being to those who come soon after us," said Rep. Doug Walgren of Pennsylvania.

## HOME

(Continued from Page 7)

assembling an engine when this reporter called on him. "It would be nice to meet other kids my age and play games," he offered. He is also going to Camp Fantastic this year for the first time and doesn't know any kids either.

Danny Martin, 13, a patient from Westerport, Md., has been in the CC for 19 cycles of chemotherapy since July 1987. His mother, Carole, comes and stays with him.

"I always have to be prepared to stay when he comes and last time we were here for 2 weeks," she said.

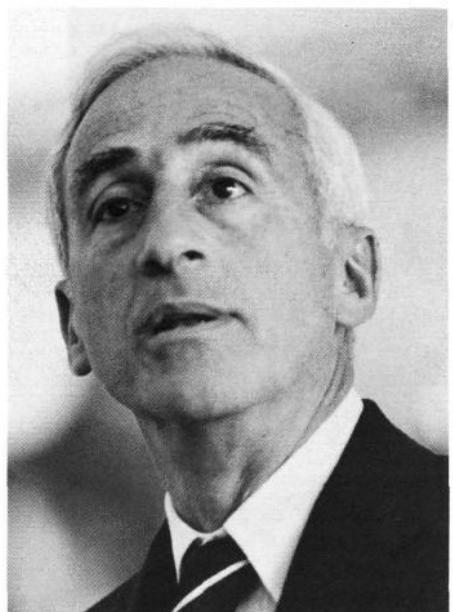
"Sometimes I bring Danny's favorite soup with me and then I have to find a kitchen."

Danny was excited about the possibility of a game room in the Inn; now he mostly uses the computer room on 13 West. Also, his sister, Diana, age 11, will be able to visit and play games with him.

The feelings of excitement about the Inn and what it will mean to the patients and their families can be summed up in one statement—it will be like a second home.—Anne Barber



"At first glance, the people who come to NIH for treatment seem very diverse," said Cindy White, mother of a young cancer patient here. "But we're bound together by two powerful factors—fear and hope for success."



Dr. P. Roy Vagelos spent 10 years on the NIH campus as a researcher prior to joining Merck.



"NIH is going to be a home where they embrace you and where no one will ever be turned away," said Rep. Connie Morella of Montgomery County.



Developer Alan Kay will oversee construction of the Inn as a "pro bono publico" project.



"It won't be long before people say, 'NIH? That's where the Children's Inn is,'" said Dr. William Raub, NIH deputy director.

Children wielding plastic shovels joined in the groundbreaking ceremony for The Children's Inn at NIH on July 29. Completion of the project, located on the north side of the NIH campus, is slated for next summer. The home will house up to 36 families participating in research studies at NIH.

## SPEECH

(Continued from Page 1)

director of a major research study on adductor spasmodic dysphonia (now in its third year), said in a recent interview. She is head of the NINCDS Speech and Voice Unit.

"We've seen some real speech changes," Ludlow said. "People who had lost all confidence (due to their speech affliction) are now back at work, gregarious, and able to answer the phone."

Exactly what causes SD, how many suffer from it, and a cure for it are unknown. Ludlow believes hundreds of men and women are afflicted. It often strikes in the most productive years, between 30 and 50 years of age. In 50 to 60 percent of her patients, the symptoms first appeared after a bad cold. "We suspect the cause could be viral, but we don't know," Ludlow said.

The trial lawyer—who will be called Jim here—followed a typical pattern in voice control loss, according to Ludlow. "After an upper respiratory infection, he developed laryngitis which then seemed to go away," Ludlow said. "But a month later he noticed cracks in his voice and a hoarseness."

Jim's private physician referred him to specialists to search for a tissue problem such as a growth or cancer. As his voice became more difficult to control, Jim saw a speech therapist who treated him for 6 months with no results. Subsequent treatment included medication such as Valium and other relaxants.

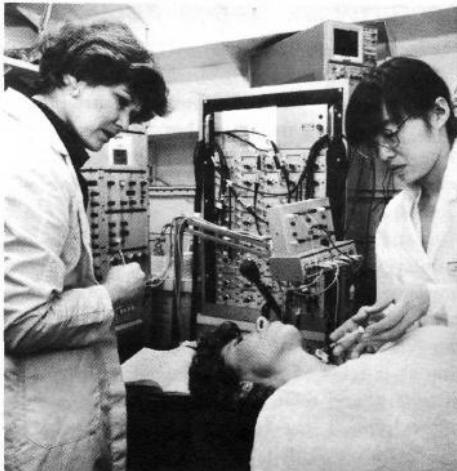
During the next 6 years the problem continued with still no accurate diagnosis. Ludlow said stories of misdiagnosis among SD sufferers are common. One patient in the study said it was 17 years before she was correctly diagnosed as having the dysphonia. Some spend years in speech therapy or even psychological therapy for the problem that stems from uncontrolled muscle spasms causing overly tight vocal cords.

"The disorder has sent patients into speech therapy, hypnosis, psychoanalysis, and even acupuncture," Ludlow said.

Proper diagnosis in Ludlow's study is through fiberoptic laryngoscopy, which involves threading a tube through the nose and into the throat to sit above the vocal cords. "We film the vocal cords and watch them move," Ludlow said.

When the vocal cords function normally, they act as reeds in a woodwind instrument. The lungs force air between them producing speech. Adductor spasmodic dysphonia occurs when the vocal cords, also known as vocal folds, are abnormally tight and normal movement cannot occur.

SD sufferers typically cut off words too soon



Dr. Christy Ludlow (l) and her assistant Dr. Mihoko Daito inject botulinum into the vocal folds of patients with spasmodic dysphonia, a voice disorder. The treatment temporarily restores the voices of afflicted patients.

and instead emit rushes of air in an attempt to open the vocal cords. Speech is effortful, slow and strained. Pitch control is frequently lost as well, resulting in a voice waver that sounds as though the speaker will burst out crying or is even mentally deficient.

"The most common worry of those who enter the study is, 'I'm going to lose my job if I don't get treatment,'" Ludlow said. "In fact, many do lose their jobs."

In designing a treatment for the disorder, Ludlow said she drew on the results of research to control an eye disorder known as blepharospasm. Five years ago, doctors began injecting eye patients with botulinum toxin to halt muscle spasms that caused uncontrolled squinting. The treatment worked.

Ludlow believed that the toxin could stop vocal cord tightening by weakening the muscles that spasm. (In past years, vocal cord surgery had temporarily eliminated some symptoms of the affliction, but they often recurred.) The present study on SD began at NIH in 1986.

A minute quantity of the botulinum toxin, which is similar to the toxin that causes the virulent, sometimes fatal food poisoning called botulism, is injected through the neck directly into the laryngeal muscles that control the vocal cords. The neck is anesthetized locally before the injection.

In paralyzing the vocal cords, the toxin interrupts communication signals from nerve to muscle, thus preventing stimulation, Ludlow said. Lacking a stimulus, the vocal cords cannot over tighten. Air then flows over them normally, and speech is no longer impeded. Improvement is usually apparent within a week of the first injection.

"We know we've been successful when we find a patient's message on our automatic answering machine," Ludlow said. For many patients, the call to Ludlow is their first phone call in years, because SD makes talking on the phone too frustrating or humiliating.

So far, normal speech has been restored to many patients, and all patients improve. The so-called Bo-tox treatments have most benefited the patients most severely afflicted, Ludlow said. Use of botulinum toxin is still limited to medical studies. The U.S. Food and Drug Administration is expected to approve soon its use for eye disorders. (The drug is currently being studied in other disorders and is used to relieve hand cramps common to writers and pianists.)

Treatment for adductor spasmodic dysphonia is available in the United States only at NIH or through Columbia Presbyterian Medical Center in New York. Treatment is also available in England and Italy.

"We are getting calls from speech pathologists, neurologists, and otolaryngologists all over the country," Ludlow said. Seventy patients are currently participating in the NIH study, and Ludlow is accepting two new patients every week.

While the treatment produces almost miraculous results within a short time, Ludlow cautions that it is not a cure for the dysphonia; it just relieves the symptoms. Symptoms recur within months of each injection, so patients usually need injections every 4 months. Two patients have gone as long as 1 year without a recurrence.

There are also side effects. Eighty percent of the study participants experience temporary swallowing problems as a result of the toxin, Ludlow said. Some also experience a temporary decrease in voice volume. But all in the study prefer to put up with the side effects of the toxin rather than forego its use.

At a time when SD sufferers have hopes of being correctly diagnosed, they are also finding a base of support. Support groups have formed in California, Kansas, New York, Texas, and Washington, D.C. A national newsletter is in preparation.

Ludlow believes that accurate diagnosis will alert more speech experts to the disorder. At the same time, she hopes to understand the physiology of the problem more clearly as the study moves into its final years.

"We're investigating whether SD is a feedback disorder," Ludlow explained, noting that the vocal cord tightening could be triggered by a lack of signals from the brain's cortex to brainstem neurons.

"We also have to look at a link between the disorder and a virus as a possible cause,"

## VOICE

### (Continued from Page 9)

Ludlow said, although doing so would be difficult because most victims become part of the NIH study long after the onset of symptoms.

Ludlow spoke with pride of the diaries that she requires be kept by people in the NIH study. "It's fascinating to watch people change from being withdrawn and insecure. They become confident and find joy in communicating—it's a real personality change."

"People are now organizing the big events in their lives around treatment schedules," Ludlow said. Trial lawyer Jim, for example, has been able to schedule most court dates to coincide with optimal treatment needs. And a career he once considered putting aside has become fulfilling again. □

### KERMIT Seminar

The DCRT Training Program is sponsoring a seminar on KERMIT on Aug. 26 at 9 a.m. in Bldg. 12A, Rm. B51.

KERMIT is a software package used to transfer files between the PC and the mainframe computer. Topics to be covered include how to install KERMIT on the PC, how to use it for file transfer and for terminal emulation.

To register for the seminar, contact the DCRT Training Unit, 496-2339, TDD 496-8294. No formal application is required. □

### Lecture/Film Series Focuses on Addiction

The NIH Employee Counseling Services will present its 1988-89 Guest Lecture/Film Series beginning in September 1988 and running through June 1989. The theme of the series is "Understanding Addiction: Causes, Consequences, and Choices."

A combination of six lectures by community experts and five films will be presented on the NIH campus from noon to 1 p.m. The purpose of this series is to educate the NIH community on the nature of addiction as it relates to drugs, alcohol, eating disorders, and relationships, and its impact on the individual, the family and the workplace.

The lectures will be held in Wilson Hall, Bldg. 1. The films will be shown in the Little Theatre, Clinical Center. Employee counselors will introduce the lectures and films and will lead a discussion period afterward. Relevant handouts will be distributed at each lecture and film.

The schedule is as follows:

Sept. 7 The Addictive Personality—From Struggle to Success  
Carol Weiss and Michael Bowler

Oct. 20 Friday Night Five, a film about driving under the influence and the symptoms of chemical dependency.

Nov. 9 Cocaine and PCP: Separating Facts from Fiction, Jacob Melamed

Dec. 1 White Lady, a film about cocaine use in all levels of business and industry.

Dec. 8 Holiday Rituals: Celebration Without Crisis, Kent Beduhn

Jan. 11, 1989 The Hungry Heart: A Look at Eating Disorders, Monica Callahan

Feb. 16 Sons and Daughters: Drugs and Booze, a film about the parental role in prevention.

Mar. 22 Drugs And Teens—A Family Affair, Lee Dogoloff

Apr. 19 Drug and Alcohol Addiction: When Someone You Know Needs Help, Scott McMillan

May 19 Pleasure Drugs: The Great American High, an NBC film about industry's fight against drug and alcohol abuse.

June 1 Family Matters, a film about how families learn to deal with the family member who has an addiction to drugs, alcohol, or food. □

### Pregnant Women Needed for Study

Will you be 34 to 36 weeks (8½ to 9 months) pregnant in November? Would you like to participate in a study of the daily changes in your body's stress response during pregnancy? If so, and you would like more information, phone Dr. Doug Rabin, (301) 654-2964. Volunteers will be reimbursed for their participation. □

### Bowlers Needed

The NIH Wednesday Night Mixed Tenpin Bowling League will need several bowlers for the 1988-89 season. They bowl at Westwood at 6 p.m. beginning Wednesday, Sept. 7. For further information, please call Betty Morris, 496-5415, or Joyce Fisher, 496-7617. □

### Clinical Center AIDS Nurses Honored by DHHS



Nancy L. Sears, clinical nurse, NIAID, and one of three NIH nurses recognized recently for their work with AIDS patients, is shown here receiving a certificate from DHHS Assistant Secretary for Health Robert Windom at a ceremony honoring nationwide AIDS nursing care.



Rose Thomas, clinical nurse, NCI, receives congratulations and a certificate from Deputy Assistant Secretary for Health Ralph Reed of DHHS commending her for "selfless dedication, compassionate service and outstanding leadership in providing direct nursing care to people with AIDS."



Christine Grady, clinical nurse specialist, NIAID, recently received a special award from DHHS Assistant Secretary for Health Robert Windom honoring her for outstanding care given to AIDS patients. Awards were presented to 13 other AIDS-care nurses from all over the country.

## TRAINING TIPS

The NIH Training Center of the Division of Personnel Management offers the following:

### Courses and Programs Dates

#### Management and Supervisory 496-6371

Networking: Silent Politics	9/1
Working With Difficult Employees	9/7
Report Writing	9/13
Conducting Effective Meetings	9/22
Dealing With Daily Conflicts	9/14
Working With Personal Differences: Advanced MBTI	9/27
Managing Behavior in the Work Environment	10/26
Working with Personal Differences: MBTI I for Technical & Support	10/12
Working With Personal Differences: MBTI I for GS-12 and above	10/19

#### Office Skills 496-6211

Basic Time & Attendance	9/1
Travel Orders & Vouchers	9/26

#### Adult Education 496-6211

#### Training and Development Services 496-6211

Personal Computer training is available through User Resource Center (URC) self study courses. There is no cost to NIH employees for these hands-on sessions. The URC hours are:

Monday-Thursday	8:30 a.m.-9:00 p.m.
Friday	8:30 a.m.-4:30 p.m.
Saturday	9:00 a.m.-3:00 p.m.

NOW AVAILABLE ON SHARE TRAINING FY 88 Training Center courses

Access Wylbur and enter SHARE TRAINING.

First time users only, enter:  
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## Coma Video To Be Shown at NIH

*Surviving Coma: The Journey Back*, a heart-warming video about young adults' experiences during and following coma, will be presented by NINCDS on Aug. 23 from 12:30 to 1:30 p.m. at the following locations:

Bldg. 36, Conf. Rm. 1B-13  
Bldg. 10, Lipsett Auditorium  
Bldg. 31, 8th Fl. Conf. Rm.  
Bldg. 1, Rm. 114  
Federal Bldg., Rm. B1-19

This video has been shown on public television. It was produced by the Sunny von Bulow Coma and Head Trauma Research Foundation in New York. □

## NCNR Director Honored

Dr. Ada Sue Hinshaw, director of the National Center for Nursing Research, recently received several awards. The Elizabeth McWilliams Miller Award for Excellence in Nursing Research was given to her by Sigma Theta Tau International. The nursing honorary society cited her "notable contributions to the nursing profession as principal investigator of several nationally funded projects and for numerous leadership roles in promoting nursing research."

Hinshaw also received two honorary doctor of science degrees for distinguished contributions to nursing education and research, one from the University of Maryland and another from the Medical College of Ohio.

Hinshaw has received many awards for leadership in nursing research and education. Her research accomplishments include the development of measures to assess psychosocial factors such as patient recovery patterns, patient self-care methods and patient satisfaction with nursing care. She also has conducted studies on the factors influencing the retention of professional nurses in hospitals, and the effects on



Dr. Ada Sue Hinshaw

patients of certain types of training for geriatric caregivers.

The NIH National Center for Nursing Research was established in April 1986 and Hinshaw became its first permanent director in June 1987. □

## Mary Jane Talley Dies; Was NCI Biologist for 35 Years

Mary Jane Talley died on Saturday, June 4 after a year-long illness. She had worked as a biologist at the National Cancer Institute for 35 years.

In January 1988 she was honored by the Division of Cancer Biology and Diagnosis

in recognition of her long and distinguished service. She coauthored a number of scientific publications in diverse areas including radiation biology, pharmacology and immunology.

For the last 6 years Talley worked with Dr. John Weinstein in the Laboratory of Mathematical Biology, making important contributions to the work of the group on monoclonal antibodies for diagnosis and treatment of cancers. Her working relationships were characterized by straightforward honesty and a light touch that endeared her to everyone with whom she worked.

Talley was very active in community organizations, among them the Pleasant View Historical Association. She was also an active church member and taught Sunday school at the Brooke Grove United Methodist Church.

She is survived by her husband, Willard W. Talley, Sr., by six children (including Joan B. Talley at NIDDK), and by 19 grandchildren. Donations can be made in her name to the Pleasant View Historical Association, 11810 Darnestown Rd., Gaithersburg, MD 20877. □



Mary Jane Talley

## Super Supervisor Recognized

Willard Daellenbach had no idea his employees thought so highly of him. So it came as a complete surprise when he recently received the outstanding supervisor of the year award from the University of Maryland Cooperative Education Program.

The work-study program, which allows students to alternate semesters of actual on-job experience with semesters of coursework, recognizes certain supervisors as superior based upon essays written by the students.

In only his second year at NIH as special assistant to the chief of the Design and Construction Branch, DES, Daellenbach already has been nominated for branch employee of the year honors as well as for the DES director's award.

"We have a pretty good relationship in our office," he said. "There's a team spirit."

Daellenbach's colleagues think he's at least partially responsible for the spirit of the office.

"Will created a supportive and comfortable atmosphere to work in," explains Sheryl Miller, procurement assistant and former employee under Daellenbach. "He's very understanding and patient."

Cynthia Guerra, co-op student and author of the essay that prompted the program to honor her one-time supervisor, agrees with Miller's assessment.

"I've learned so much from him," said the accounting major, who is considering a career



Cynthia Guerra and Will Daellenbach

in government. "He spent a lot of time explaining processes and orienting me here."

Guerra, a graduate of John F. Kennedy High School in Wheaton, came to work at NIH last January. Daellenbach encouraged her to get involved in many areas of construction contracting. "He was very supportive and nice," she said. "And even though he's no longer my boss, he continues to be helpful."

Before coming to NIH, Daellenbach worked with the Indian Health Service in California, New Mexico, Nevada and various locations nationwide as a PHS commissioned officer.

"I liked the West," he admits. "But this area has its advantages, also. The relatively stable economy and the employment opportunities are great benefits here." —Carla Garnett □

## AIDS Education Challenges Advertising Pros

In addition to being a devastating crisis to patients and health care workers, AIDS is also a public relations nightmare, according to advertising experts who spoke recently to NIH information officers.

Last July, the Centers for Disease Control retained the services of New York advertising giant Ogilvy and Mather to handle nationwide AIDS education advertising. Operating on a budget of more than \$10 million for two years, the firm was charged with distilling the knowledge of the federal government's top AIDS experts into television advertisements (some as short as 15 seconds), radio spots, print ads and direct mailing to all households in the U.S. (the "Understanding AIDS" brochure).

Unlike toothpaste, chocolate bars and automobiles, however, AIDS doesn't lend itself to an easy marketing message. And between such competing sources of information as *Cosmopolitan* magazine and the latest book by Masters and Johnson, public perception of the disease is literally up for grabs.

"AIDS doesn't offer a single message that advertising and public relations people can use to their advantage and pound home over and

over again," said a spokesman for Ogilvy and Mather, a company that was hired to produce "America Responds to AIDS," the federal government's largest single public service campaign ever. "It's an almost impossible challenge."

Adding to the problem is a reluctance on the part of any authority—civic, religious or medical—to offer firm counsel on such sensitive matters as sex, drugs and poverty to a nation as diverse as America.

To find out who their audience was and how best to reach it, the advertisers polled some 450 people nationwide who met in 18 separate "focus groups" that were studied by marketing executives. They found that Americans, by and large, have fairly good knowledge about AIDS but a relatively low level of belief in what they know. For example, while many people "know" that AIDS cannot be transmitted by a handshake, few would risk doing so.

The advertisers decided that the most effective form of AIDS education would be expressed as simply as possible and would harness the authority of the federal government as chief source of reliable information.

## FAES Announces Fall Classes

The FAES Graduate School at NIH announces the schedule of courses for the fall semester. The evening classes sponsored by the Foundation for Advanced Education in the Sciences will be given on the NIH campus.

Tuition is \$40 per credit hour, and courses may be taken for credit or audit. Courses that qualify for institute support as training should be cleared with the supervisors and administrative officers as soon as possible.

Courses are offered in biochemistry, biology, chemistry, mathematics, medicine, pharmacology, toxicology, immunology, microbiology, psychology, psychiatry, statistics, languages, administration and courses of general interest.

It is often possible to transfer credits earned to other institutions for degree work, and many courses are approved for AMA Category I Credit.

Classes will begin Sept. 19, and registration will be held from Sept. 7 through 13. Fall catalogs are available in the Graduate School office in Bldg. 60, Suite 230, the Foundation Bookstore, Bldg. 10, Rm. B1-L-101 and in the Business Office, Bldg. 10, Rm. B1-C-18. To have one sent, call 496-7977. □

The theme, "It's not who you are, it's what you do," was used to emphasize that AIDS can be prevented. It also stresses that AIDS is not necessarily a gay problem or a black problem or a Hispanic problem, but a behavior problem.

The CDC has six goals in mind for its two-year education campaign, now half over. It wants a minimum of 100 U.S. communities to sponsor well-organized AIDS education programs; three of the programs should be successful enough to be demonstration models; surveys of public opinion should show an increase in AIDS knowledge; the surveys should also show an increase in prevention of new AIDS cases through education; levels of funding contributed by federal, state and local governments for AIDS education should rise; and hard-to-reach publics, such as poorly educated IV drug abusers, should be informed.

Regarding the nationwide mailing of 107 million English language versions of the "Understanding AIDS" brochure, the CDC said that only 885 complaints—or fewer than 1 in 100,000—have been lodged so far. Among the brickbats: "Why wasn't this material mailed out sooner?" □